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**Nurses' Lived Experience of Spirituality in Relation to Helping Patients
Cope with Loss in Situations of Chronic and Terminal Illness**

by

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Canterbury Christ Church University

**Thesis submitted
for the Degree of Doctor of Philosophy**

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Abstract

This qualitative study explores spiritual issues in relation to coping with loss in situations of chronic and terminal illness. An Heideggerian hermeneutic phenomenological approach was chosen as the most appropriate methodology for exploring nurses' lived experience of utilising spirituality as a means of helping patients cope with loss. My prior knowledge both brought me to the subject of study and influenced my interpretation of data. To ensure transparency of method this prior knowledge is outlined in my fore-structure of understanding.

A purposive sample of 12 registered nurses, 5 from hospice, 4 from community practice and 3 from a nursing home setting participated in semi-structured interviews. A stepped process of analysis of interview texts produced overarching themes which are illustrated with excerpts that collectively produce a 'thick enough description' intended to facilitate understanding of my interpretation of data by those who chose to read this study. Findings were illuminated by drawing on existing theoretical knowledge and concepts.

My research diary and notes at interview constituted a research journal that recorded how my knowledge and understanding developed through my reflection on, and reflexive response to interview data. In this way my research journal was used to illuminate the research process.

There are an increasing number of studies that consider spirituality in healthcare and how patients' spiritual needs can be recognised and fulfilled. However, this study provides a different perspective, in particular, examples of how nurses' development as persons may render them not only a spiritual resource in themselves, but also, contribute to how they become proficient in spiritual care in situations of loss. There were four overriding ways in which the development of this aptitude was evident. Firstly, belief provided them with a means of coming to an understanding of why things happen and so helped them accommodate repeated exposure to patients' grief. Secondly, being a spiritual carer involved establishing a relationship with patients through 'connected' communication. Thirdly, becoming proficient in spiritual care was reflected by an increasing maturity in engaging with patients' real life and death issues, which was sustained by taking 'time out' to reconnect with the self. Finally, belonging to a team whose culture reflected a spirit of reciprocal support was crucial when patient care was emotionally demanding.

Chapter 1

Introduction

This study is situated in the South East of England and explores practicing nurses' experience of spirituality as a resource in end of life care. My interest in spirituality as a concept relevant to, initially nursing practice, and more recently health and social care, was triggered by practical need. Nurse education became subsumed in institutions of Higher Education in the late 1980s and early 1990s as part of what was called Project 2000 (UKCC, 1986). This change resulted in a shift in my employment from being a health service employee, as a Nurse Tutor, to becoming a Senior Lecturer in Nursing Studies in an Institution of Higher Education. The Project 2000 curriculum was designed to prepare a new style knowledgeable practitioner (Watkins, 1991) and differed significantly from that of Schools of Nursing. My first experience of delivering the new curriculum was in a course that constituted the first part of the second half of the pre registration programme that specifically prepared nurses for the 'branch', or focus, of nursing that they had opted to pursue as qualified practitioners. My own professional background was that of a registered general nurse and I found myself course coordinator for the multiple groups that constituted the adult branch nursing students and taught one of these groups.

Nursing models were particularly popular at the time, and this course had been loosely framed on a specific model used by most practice placement areas for adult nursing students. The taught component of the course allocated 12 hours to each aspect of care identified and one of these was spirituality. It had been my experience in schools of nursing that this aspect of the curriculum had been covered by a session with each of the various denominations of hospital chaplains and a visit from a representative of The Gideons who presented each student nurse with a copy of the New Testament. Although the 1980's had seen changes in nursing curriculum embracing a more holistic focus on care, these had incorporated the social and psychological needs of patients alongside the very well established focus on physical care, rather than explicitly addressing spiritual need. I had little choice with so limited

experience of teaching spirituality other than to initiate an exploration of this subject. I found the topic fascinating and have continued my personal and professional exploration of this subject ever since.

Coincidentally at the same time, as part of my own personal and professional development and as a requirement for employment within Higher Education I was undertaking a Master of Arts degree in education. My dissertation completed in the mid 1990s provided the perfect opportunity to perform an evaluative study of the effectiveness of my teaching spirituality in the pre-registration programme, as well as collate my peers' view on this topic (Greenstreet, 1996). The conclusions of this study identified the need to consider spirituality as a wide concept incorporating, but not equating it with, religion when studied within health care contexts. It also indicated that spirituality within holistic care needed to be explored rather than taught. The study provided evidence that progression in achieving learning after theoretical input on spirituality was largely sustained for the duration of the pre-registration programme.

Some years later I attempted a follow up study of the students who had been research participants during my Masters' study (Greenstreet, 2004a). My purpose was to determine whether, over a period of several years, pre-registration learning concerning spiritual care had endured, developed and been evidenced by an ability of participants to act as role models in practice. Unfortunately, it was difficult to trace participants, but those who did respond had clearly sustained their learning and gave examples of how spiritual care was demonstrated in their practice environments.

The late 1990s saw a dual development, the synthesis of which has brought me to this PhD study. Firstly, a new portfolio of educational provision for post-registration nurses included a module on the human experience of disability and I was invited to contribute 8 hours. I found post-registration students avidly interested in spirituality as a concept concerned with meaning, and making sense of situations. They readily related to issues concerning ultimate questions in which patients' wanted to know 'why' disability had

happened to them. At module evaluation they were keen for more. I enthusiastically created a whole module concerning spirituality as a perspective of care as part of the same post registration curriculum provision. I was also invited to contribute to a Masters module in a neighbouring University concerning spirituality in palliative care.

The second development was my return to study as a postgraduate student of psychosocial palliative care and my development of curriculum in relation to palliative care, and specifically modules on loss in post-registration and postgraduate programmes.

My scholarship in both spirituality and loss in health care contexts has been explored and shared in publications that address why (Greenstreet, 2004) and how (Greenstreet, 2005a) to teach loss to health and social care students, pain (Greenstreet, 2001) and curriculum development in palliative care (Greenstreet, 2005b), literature review of teaching spirituality (Greenstreet, 1999), spirituality in organisations (Greenstreet, 2005c), and contemporary discourse in spirituality (Greenstreet, 2007). A decade of experience in teaching spirituality culminated in my authoring half of a reader that considers integration of spirituality in health and social care practice, which I also edited (Greenstreet, 2006a). Significant loss challenges our assumptive world and potentially creates a spiritual crisis (Agrimson and Taft, 2008) in generating a search to make sense of unwanted change that has been thrust upon us. My studies have brought me back to the questions explored with those post-registration nursing students considering the human experience of disability, the questions asked by those living with chronic and terminal illness have a similar ring and my initial thoughts on how patients make sense of this and cope have also been published (Greenstreet, 2006b).

Collectively these experiences have brought me to this research focused on gaining a better understanding of spirituality in relation to coping with loss in situations of advanced chronic or terminal illness which often involve a sense of, or actual, loss. However, the justification for this study was grounded on more than practice experience and personal interest; it was also congruent

with government policy on health care development. Hospice care is accessible to a minority of patients and almost exclusively to those with cancer. The Department of Health (DoH) Working Paper concerning End of Life Strategy (September 2006) reflected an increasing emphasis on the need for the principles of care exemplified in hospice, to be made available to those with *'advanced, progressive, incurable illness'... 'in all settings'* (p.3). The intention was to ensure that care is holistic and *'delivered in accordance with best practice'*, to minimise not only physical but also *'psychological or spiritual suffering'* (p.6). The working paper also acknowledged that many patients have unmet spiritual and psychological needs and that carers have similar needs both during the patient's illness and in bereavement (p.7). The working paper predicted that the emergent End of Life Care Strategy would need to focus not only on the 'what' should be done but also the 'how' (p.3). The End of Life Care Strategy (DoH, 2008) that followed has ratified these proposals in aiming to bring high quality care for all people approaching the end of life, regardless of *'age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic status'*, and this should be available *'at home, in a care home, in a hospital, in a hospice or elsewhere'* (p.33). Further affirmation is evident in the strategy's ten objectives, one of which intends *'to ensure that all those approaching the end of life, have access to physical, psychological, social and spiritual care'* (p.33).

Fundamentally, the aim of the study was to explore nurses' lived experience of utilising spirituality as a means of helping patients to cope with loss associated with terminal or chronic disease. The study objectives were threefold. Firstly, to gain an understanding of nurses' perceptions of spirituality as an aspect of person-centred care, secondly, to explore the extent to which nurses facilitate spirituality as a source of coping, and finally, to explore how nurses use their personal resources in caring for those with chronic and terminal conditions. Research participants were recruited from community, care home and hospice settings where these patients are cared for.

This study is important because in exploring the significance of spirituality to nurses providing end of life care, it adds a new perspective to the existing

knowledge base. In particular, it illuminates what and how nurses contribute to these aspects of care in both institutional and community settings. It also considers how nurses, as professional carers, cope with their own existential questioning in the face of others' suffering.

Central to the concept of spirituality in health care is a concern with, and an attempt to make sense of, circumstances and outcomes of illness. In situations of loss, whether associated with chronic disease, degenerative disease or terminal illness and bereavement, individuals seek to know why? Questions of meaning are likely to be complex. In linking past research on spirituality in health care, with studies on loss and bereavement associated with professional roles, this study furthers knowledge of nurses responses to spiritual questions and how they apply these to their professional practice.

A study that links spirituality and coping in health care contexts was suited to a qualitative research design in its attempt to discover nurses' experience to generate an understanding of their roles in this aspect of care. Following consideration of potential qualitative methodologies for this study made in chapter 2, the phenomenological view of experience seemed to make this the most appropriate choice of methodology. The association of the concept of spirituality with a search for meaning (Greenstreet, 2006c) sits well with the phenomenological stance that experience is one of interrelated meanings that are bound in a totality known as 'lifeworld', and so, '*human meanings are the key to the study of lived experience*' (Ashworth, 2003 p.13). However, the implicit nature of personal spirituality (Greenstreet, 2006c) makes the requirement of disciplined 'bracketing' of preconceptions in Husserlian phenomenology (Giorgi and Giorgi, 2003) unrealistic. Therefore, a Heideggerian (1962) hermeneutic phenomenological approach that pre-supposes prior understanding on the part of the researcher (Polit and Beck, 2010) offered a more appropriate methodology for this study.

In acknowledging that it was my fore-structure of understanding that brought me to the topic and focus of this research, hermeneutic phenomenology as methodology requires me to situate myself in relation to the research topic and

its participants so that I could remain conscious of how my fore-knowledge influenced my interpretation of data. For this reason, chapter 3 considers what is meant by my fore-understanding and includes an initial literature review that reflects the synthesis of my study and experience prior to this research in how spirituality is related to coping for those with chronic and terminal illness. Consequently, chapter 3 inevitably includes material from my published work.

Data collection is addressed in chapter 4. Research participants were identified through purposive sampling of nurses involved with end of life care in hospice, community and care home settings within South East England. Exclusion criteria therefore included acute settings, practice contexts where patient throughput is rapid and those outside of South East England. The size of the sample was determined by the number of participants interviewed until adequacy of data was reached. Interviews obtaining descriptions of participants' experience of spirituality in relation to coping with loss were the primary means of data collection for this study. The use of a topic guide helped direct conversation toward the phenomena studied and result in interviews being designated as semi-structured. This methodology is reflexive in that it uses the researcher's fore-understanding to address the phenomena that is then challenged in the interrogating experience of interview through a process that intrinsically involves self-critique and allows the researcher to move beyond the partiality of previous understandings (Finlay, 2003). There is also a duality of interpretation in the use of this methodology where the researcher tries to make sense of the participants trying to make sense of their world (i.e. the double hermeneutic) (Brogden, 2010).

The process of analysis of data constitutes chapter 5. A stepped approach to analysis, closely reflecting the scheme of Smith et al (2009), was chosen as a tool to address the process of engaging with, and interpreting the meaning of the 'lived experience' documented in the transcripts of semi-structured interviews with the participants. This process started by looking at one transcript, and then moving on to the others one by one. The emergent themes were then listed to facilitate the analytical or theoretical ordering necessary to

elicit connections between them. Some consideration of reflexivity and analysis of my diary documenting reflection on research process was also included in this section.

Chapter 6, in which the study findings are considered, marks the emerging shift in my own knowledge and understanding of the phenomena studied. This is developed in discussion supported by further literature review, and so made explicit, in Chapter 7. My fore-structure of understanding and scholarship, evidenced in publication, had largely been focused on ‘nursing’ and preparing nurses to nurse. This study however, has focused on ‘the nurse’ themselves. In this way the contribution of the nurse’s development as a person and ‘how’ that impacts their sensitivity, and ability, to provide spiritual care for patients has become evident. Their personal philosophy or beliefs, skills in ‘connected’ communication, an increasing maturity in engaging with patients’ real life and death issues, together with, the ability to manage personal vulnerability, collectively enabled and sustained participants in their facilitation of spirituality as a resource for patients coping with loss. The study concludes with recommendations for practice, education and research which constitutes chapter 8.

To start then, the justification for the claim that the aim of the study is best suited to a Heideggerian hermeneutic phenomenological methodology unfolds in the following chapter.

Chapter 2

Methodology

2.1 Introduction

Methodology is often simplistically classified as either quantitative or qualitative; the former involving methods dealing with quantity and numbers and the latter quality and description (Parahoo, 1997). The reality is that the melee of methodologies and methods available, together with inconsistent use of related terminology can generate confusion that hampers clarity of construction of research process. This is a significant issue given that account of this process is so crucial in the justification of the value of the research (Crotty, 1998).

This chapter explains the choice of approach for this research, where the focus of study is centred on gaining an understanding of nurses' perceptions of the meaning and use of spirituality in care of patients facing the challenges inherent in advanced chronic or terminal illness, which often involve a sense of, or actual, loss. Methodology reflects the theory of knowledge that informs the assumptions being made in relation to the focus of study. Therefore, the chapter commences with an exploration of epistemological, ontological, and theoretical perspectives, the outcome of which suggests that a study focused on 'lived experience' is not one that is amenable to a positivist, or quantitative, method. In attempting to quantify or reduce experience to enable empirical measurement the very essence of the phenomena of study would be destroyed. Consequently, a qualitative approach is the more appropriate choice in this instance.

There are a range of interpretative philosophical and theoretical perspectives that can be described as constituting a qualitative paradigm. Of these, phenomenology focuses on the lived experience of individual research participants. This chapter explains why an Heideggerian hermeneutic phenomenological approach best supports this study, which is focused on the nurse participants' lived experience of spirituality as a resource in coping with loss. It also explains the method adopted for this study; the use of semi-structured interviews and the contribution of reflexivity.

2.2 Identifying Epistemological Stance

The term 'epistemology' is concerned with the study of the nature of knowledge, and asks 'what we know and how we know it' (Cook, 1988 p.225). Such questions are helpful in drawing attention to the parameters of knowing and shared boundaries with uncertainty and doubt. The very nature of research is to seek new knowledge and consequently some consideration of epistemological stance is crucial in determining research design.

Objectivist epistemology '*...holds that meaning and therefore meaningful reality exists as such apart from the operation of consciousness*' (Crotty, 1998 p.8). This stance does not relate well to a research study that is focused on the concepts of loss, spirituality and coping and the 'lived experience' of nurses. Concepts by their very nature are products of consciousness and experience (Dilthey, 1976). Similarly, an objectivist view neglects the personal nature of knowing described by Polanyi (1969) as tacit knowledge, when we know more than we can express or vocalise. Spirituality is described as an essentially unifying link between the deeply personal and the universal (Culliford, 2002) and therefore any study concerned with this concept is rooted in epistemology that acknowledges personal, conscious and unconscious forms of knowing.

More relevant to this study is constructionism, defined by Crotty (1998) as reflecting that:

'...all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context.' (p.42)

This supports the suggestion that the meanings directed toward certain objects are subjective (Creswell, 2007) and that, meaning is not inherent within an object but emerges when consciousness engages with that object. Therefore, meaning is not created but constructed. In this way constructionism supports the dual perspective of spirituality as both deeply personal but linked to the universal. This is exemplified by McColl (2000) who describes spirit as

existing independently, and the human characteristic of spirituality as the means by which spirit is made meaningful and incorporated into our lives according to our ability to experience it.

Terminology that clearly differentiates between nuances of closely related epistemologies can help to determine which particular stance accounts for the research process being considered for this healthcare study. In differentiating between the terms 'constructivism' and 'constructionism' Crotty (1998) describes the former as '*the meaning-making activity of the individual mind*'. This view respects and therefore accepts the validity of each individual's way of making sense of their world but does not lend itself to any sense of critique. He compares this with constructionism, '*where the focus includes the collective generation (and transmission) of meaning*' (p.58) and therefore emphasises the impact of culture on world view. Nurses working within health settings share a collective professional culture in their approach to those in their care. In this way the personal meaning making of concepts such as spirituality and loss will impact their worldview in the way described by the term constructivism, but socialisation into the profession of nursing will require subsuming personal belief to the collective requirement of professionalisation. Professional conduct is subject to both public scrutiny and statutory regulation which have a powerful influence on nurses' world view of their work, including aspects of care related to loss and spirituality. The collective generation and transmission of meaning related to loss and spirituality in health care and the consequent impact on nurses' world view, is therefore, better described by the term social constructionism.

Another benefit of social constructionism in relation to research design is that it inherently supports critique. However, Crotty (1998) warns of the need to avoid '*reification*' resulting in '*the sense we make of things*' becoming '*the way things are*' (p.59). He also encourages avoiding '*sedimentation*' when layers of interpretation can distance existential engagement from realities (p.59). Hence, this research study may benefit from avoiding prescriptive interpretation in relation to spirituality as a resource in coping on the one

hand, and too nebulous a theoretical interpretation of this intangible concept for it to engage with reality on the other hand.

Alongside epistemology, research exploring spirituality as a resource draws on ontology. Sartre (1958) describes ontology as '*concerned solely with what is*' (p.229) and as '*Being itself, the condition by which "there is" a world, a human reality*' (p.233). This is interpreted in relation to qualitative enquiry by Creswell's (2007) description of ontological issues as being concerned with the multiple realities of the researcher and the participants being studied. Therefore, quoting examples of the participants' actual words and the researcher's reflexive thoughts can evidence different nurses' realities and how they view their 'lived experience' differently, as well as the researcher's changing reality in relation to understanding the spiritual resources utilised in coping in healthcare contexts.

2.3 Philosophical and Theoretical Perspectives

2.3a Elimination of Positivism as Relevant to this Study

Objectivist epistemology is inherent in the theoretical perspective of positivism. The initiation of the term 'positivism' has been attributed to Auguste Comte (Crotty, 1998) who purported an objective approach to social enquiry. Interestingly, he considered that all knowledge '*consists in a description of the coexistence and succession of phenomena*' (Passmore, 1966 p.14) and that positivism constituted the last stage in the development of enquiry. The first stage had been theological enquiry when men explained phenomena as random acts of spiritual beings. The second stage of metaphysical enquiry saw the substitution of "powers" or "faculties" or "essences" for spirits (Passmore, 1966 p.14). In the final and third stage, Comte advocates that scientific laws can be established by observation, experiment and comparison of the relationship between phenomena. In applying this to the social sciences Comte does recognise human consciousness in that it is determined by 'the social' (Crotty, 1998 p.22). However, research focused on spiritual resources in relation to coping with loss draws on theological, philosophical and psychological enquiry situated outside of Comte's positivism.

Other ‘shades’ of positivism appear even more irrelevant to the focus of this research. An example is logical positivism which includes Wittgenstein’s ‘*principle of verifiability*’ (Crotty, 1998, p.24). Although a deeply spiritual man, Wittgenstein’s work was developed into a ‘virulent anti-metaphysic’ form of positivism (Strathern, 1996 p.49-50) which considered only verifiable statements as meaningful. Verifiable statements concern definition of the subject. Verifying a definition of spirituality has proved to be elusive. Various attempts have been made to collate individual thought to produce a definition but outcomes remain nebulous, for example, some refer to spirituality as to do with transcendence (O’Brien, 1982; Hover-Kramer, 1989), or, unfolding mystery (Burkhardt, 1989) or the depth of all being (Harrison and Burnard, 1993). These all reflect subjective rather than verifiable statements.

Post positivism offers a hybrid theoretical perspective that facilitates the traditional quantitative researcher in health sciences to shift to a qualitative focus. The post positive researcher differs from positivist colleagues in supporting the need for multiple perspectives rather than a single reality. However, post positivism maintains an emphasis on empirical data collection and compiling scientific reports (Creswell, 2007) and so is not conducive to a study focused on life experience that uses subjective account as data.

Hughes (1990) describes the significant shift in view of positive science that followed the emergence of Popper’s theory of Falsification. Popper (1972) did not accept that science could verify truth, but that truth is tested by the process of eliminating falsehood. Consequently, the proposal refuted that scientific knowledge should come from the empirical testing of theory and proposed instead that it should rely on ‘bold conjectures’ or hypotheses that are yet to be proved wrong (Hughes, 1990). The move away from generalisations inferred from specific findings to deductive reasoning driven by a search for refuting ‘*conjectural hypotheses*’ affirms the ‘tentativeness’ of scientific theory (McLaughlin, 2007 p.27). However, post positivism still fails to acknowledge the significance of the ‘lived’ experience of participants so central to this research. In research that is focused on understanding the

spiritual resources of persons, values, feelings and emotions are of great significance in the expression of subjective meaning of lived experience (van Manen, 1997). Therefore, a study that draws on subjective account requires an alternative epistemology and theoretical perspectives in research design.

2.3b Justifying Interpretivism as Relevant to the Study

Constructionism established meaningful reality as not discovered but constructed and contingent on human interaction within social contexts, in contrast to objectivism's notion that truth and meaning reside in their objects independent of consciousness (Crotty, 1998). In much the same way interpretivism has emerged as an alternative theoretical perspective to positivism. Rather than positivism's focus on causality and general laws, interpretivism is concerned with understanding and so explaining human and social reality (van Manen, 1997). Therefore, research underpinned by interpretivist theoretical perspectives is inherently qualitative. A qualitative stance is often based on the premise that knowledge about humans is not possible without the humans involved describing their 'lived' experience themselves (Polit and Hungler, 1989).

Methodologies underpinned by interpretative theoretical assumptions differ in their focus. Examples of such methodologies are grounded theory, ethnography and phenomenology. Grounded theory focuses on social processes, such as, the study of individual processes or interpersonal relations. Continuous interplay between analysis and data collection culminates in interpretation which identifies patterned relationships within categories of data (Charmaz, 2003; Holliday, 2007)). Ethnography is concerned with understanding cultures and traditions (Cohen, 2000; Maggs-Rapport, 2001). It involves participant observation, unstructured data collection, a sample of a small number of cases and interpretation of the meanings and functions within the data (Holliday, 2007).

Phenomenology is both a school of philosophical thought and a research methodology concerned with meaning and lived experience. 'What sets ...phenomenology apart' from other interpretative approaches is 'the tradition

of looking at phenomenon, a single kind of human experience rather than a social process or structure or a culture' (Cohen, 2000 p. 8) The study of phenomena, the appearance of 'things' in their natural context, rather than noumena, the things themselves, portrays 'the everyday unreflected attitude of naïve belief' (Cohen, 1987 p.31) which constitutes the lived experience of individual research participants.

Richards (2005) points out that the 'excitement and terror' (p.125) of qualitative research is that it is not possible to know at the start where it will end. It is for this reason that it is important to remain focused on the aim of a study, particularly in the choice of methodology to ensure 'best fit' for the research in hand. My aim is to explore nurses' lived experience of the phenomena of spirituality as a means of facilitating patients coping with loss associated with terminal or chronic disease. I am not 'looking at' a social process within nursing, (although social process may be part of nurses' lived experience), and so, grounded theory is not an appropriate choice of methodology for this study. I am not focused on describing a particular nursing group or culture, (although culture and traditions may be part of nurses' lived experience), and therefore ethnography is also not an appropriate methodology for this research. However, I am focused on a particular 'lived experience' of nurses in relation to the phenomena of spirituality as a resource in coping with loss. For this reason phenomenology, which facilitates the study of phenomena in their natural context and the related 'lived experience' of research participants, appears the most appropriate methodology for this study.

Hence, this study utilises the theoretical perspective of interpretivism and looks to phenomenological methodology to elicit a 'best fit' qualitative approach to investigate nurses' 'lived experiences' of spirituality in relation to coping with loss in situations of chronic and terminal illness.

2.4 Phenomenological Methodology

The historical development of phenomenology is described by Spiegelberg (1960a; 1960b) and Cohen (1987, 2000) as comprising phases or movements.

The German phase gave birth to the development of two styles of phenomenology which have founded the basis of a plethora of derivatives since. Initiated by Husserl (1931), the first style of German phenomenology was shaped by a descriptive philosophy. Later, Husserl's assistant, Heidegger (1962), developed an alternative interpretative style of phenomenology shaped by a hermeneutic philosophy. These founding philosophers refined their initial ideas within their lifetime. The dynamic of phenomenological philosophy and research method was continued in the French phase, for example, Merleau-Ponty (1962) retained Husserl's descriptive approach to phenomena in his proposed phenomenology of perception (which was also influenced by existential philosophy, attributed to his association with Sartre). Cohen (2000) describes the more recent schools of phenomenology, the Duquesne school influenced by Husserlian philosophy (e.g. Giorgi and Giorgi, 2003), the school of Heideggerian hermeneutics and interpretative phenomenology influenced by Heideggerian philosophy (e.g. Benner, 1984; 1994) and the Utrecht School that combines features of descriptive and interpretative phenomenology (e.g. van Manen , 1997)

2.4a Descriptive Phenomenology

Husserl (1931) proposed that phenomenology aims at being a '*descriptive theory of the essence of pure experience*' (p.209). In unpublished papers found following his death Husserl described the world of lived experience as '*life-world*' (Spielberg, 1960a p.159). Experience is believed to be '*the consciousness of something*' (Husserl, 1931 p.120) and therefore experience is said to be '*intentionally related*' (p.119) to this something. The essence of consciousness is dormant, and phenomenology the means of '*the noticing of what was previously unnoticed*' (p.120). In this way, the study of experience reveals consciousness (Cohen, 2000).

Husserl's (1931) explanatory account of phenomenology as a descriptive theory frequently couches argument in terms of 'science'. This reflects his interest in promoting philosophy as scientific (Spielberg, 1960a), requiring specific, and rigorous method to get back to the true form of the 'things' (or phenomena studied) themselves, to notice the previously unnoticed.

Husserlian philosophy is concerned with how we ‘know’ and is therefore a form of epistemological inquiry. Descriptive phenomenology requires sourcing data from accounts of conscious experience of everyday life, from the description of ‘things’ as people experience them (Polit and Beck, 2010). Processing this data involves a number of activities that are termed, reduction, bracketing, or, epoche, and intuiting.

Phenomenological reduction involves two stages (Spielberg, 1960a). The first stage is eidetic reduction, a shift from ‘*particular*’ facts to ‘*general*’ essences (Husserl, 1931 p.209-210). Although Husserl did not specify how this is achieved, eidetic reduction has been taken to mean dropping references to the individual, or the particular (Cohen and Omery, 1994). The second stage of transcendental, or phenomenological reduction proper, allows phenomena to be viewed without the distortion of preconceptions. Temporary suspension of preconceptions was described by Husserl (1931) as bracketing (or epoche). Hence, bracketing, requires the researcher to hold their preconceptions about the world, (or phenomenon studied), in abeyance while seeking to attain the true form of the ‘things’ themselves. In this way, researchers strive to avoid ‘*nonsensical confusion*’ (p.179) and confront the data in pure form. Bracketing is an ongoing process and researchers often maintain a reflexive journal to continually review the effectiveness of their efforts to bracket (Polit and Beck, 2010).

Intuiting occurs when the researcher remains open to the meanings attributed to the phenomenon by those who have experienced it (Polit and Beck, 2010). Husserl (1931) writes:

‘If it figures as a science within the limits of mere immediate intuition a pure “descriptive” science...has to place before its own eyes as instances certain pure conscious events, to bring these to complete clearness, and within this zone of clearness to subject them to analysis and the apprehension of their essence...’ (p.190)

In “looking at” the phenomenon using possibly, imagination, memory or real cases (Cohen and Omery, 1994), the original essence of experience becomes evident through deep reflection. Reflective intuitive ‘*givenness*’ (thought from within) is the means of ‘seeing’ the phenomena ‘as meant’, or, its meaning in consciousness (Ray, 1994). In this way, phenomenological study seeks to secure insights into the essence of what is given intuitively in experience, and so, produce a concrete descriptive analysis. The final process is that of description when the researcher has come to an understanding of the phenomenon, and can define it (Polit and Beck, 2010)

Merleau-Ponty (1962), a French phenomenologist, believed that true philosophy is ‘*relearning to look at the world*’ (xxiii). He supported Husserl’s idea of a return to the ‘things themselves’, using a scientific approach that was ‘*a matter of describing, not of explaining*’ (p.ix) phenomena. Hence he retained Husserl’s descriptive approach, but rather than seek the primordial essence of phenomena, Merleau-Ponty believed that original phenomena were buried in darkness and could not be brought to light, but that we could erect pointers in the darkness (Thomas, 2005). He believed that perception opens us to reality, providing a direct experience of the world:

‘All my knowledge of the world, even my scientific knowledge, is gained from my own particular point of view or from some experience of the world’ (Merleau – Ponty, 1962 p.ix)

All knowledge, opened up to us by perception, is learnt in an embodied, communal environment constituting a ‘knot of relations’ of all those we have known and encountered. Merleau-Ponty (1962), points out that ‘*it is because we are through and through compounded of relationships with the world*’ that researchers need to slacken the ‘*intentional threads*’ (xv), that connect them to the phenomena of study, so they ‘*become aware of the fact*’ and ‘*put it “out of play”*’ (p.xiv). This is achieved through the process of reduction, or, bracketing, although, Merleau-Ponty (1962), acknowledges ‘*the most important lesson which reduction teaches us is the impossibility of a complete reduction*’ (xv). What he did believe to be crucial in relation to the description

of experience as it is lived by an individual, is not what is happening, but what is perceived as happening by that person (Munhall, 1989).

Amedeo Giorgi, an American phenomenologist, is '*the originator of the descriptive phenomenological psychological method*' (Smith, 2003 p.vii). This approach is influenced by Husserlian philosophy and therefore supports the concept of intentionality, in that consciousness is always directed toward something, together with, the need for attitudinal modifications involving, bracketing, or epoche, and phenomenological reduction, to prevent bias (Giorgi and Giorgi, 2003). However, it does differ in selecting, and adapting a level of reduction that Husserl called phenomenological psychological reduction. This level of reduction is renamed and called the scientific phenomenological reduction which requires consideration of everything given to human consciousness (rather than any creatures consciousness) that is engaged with the world. The difference that scientific reduction introduces is that, objects, or states of affairs, '*are taken to be exactly as they present themselves to be, but no claim is made that they actually are the way they present themselves to be*' (p.32).

2.4b Interpretative Phenomenology

Heidegger's philosophy sees the task of phenomenology as the means of looking past the normal, everyday meanings of life, to see the truth of our Being (Cohen and Omery. 1994 p 141). Heideggerian phenomenology is therefore concerned with ontological rather than epistemological study. It is also an interpretive approach, rather than descriptive, in that it utilises hermeneutics as the means of '*interpretation and understanding of any act of communication, whether written or oral, verbal or non-verbal (such as symbols or symbolical acts)*' (Thiselton 1988, p.293).

Heidegger (1962) describes Dasein as an entity that understands its Being, in that '*its very Being, comports itself understandingly towards that Being*'. This calls '*attention to the formal concept of existence* (p.78), in that, Dasein is '*human existence*' (Speigelberg, 1960a p.282). Also, '*the fundamental structure in Dasein*' is '*Being-in-the-world*' (Heidegger, 1962 p. 65). Hence,

central to Heidegger's philosophy of phenomenology is its orientation toward experience of phenomenon 'being-in-the-world'. The meaning of experience of a phenomenon is seen to be related to context, its relatedness to the world in which it occurs. This is true for both the research participant and the researcher (Cohen and Omery, 1994).

Heideggerian phenomenology is primarily a notion of method, a mode of approaching the phenomenon of philosophical research rather than a specific, unique method. Hermeneutics as a research method rests on the ontological premise that lived experience is essentially an interpretative process (Cohen and Omery, 1994), or, as Heidegger (1962) explains, *'The Interpretation of Daesin in its everydayness'* (p.76).

Hence, it is a methodological approach intended to appropriate and interpret meaning, already implicit in lived experience (Burch, 1989). Transcripts of in depth interviews in which research participants share their experience of the phenomenon studied, provide written texts for the researcher to enter into dialogue with, and to continually question its meaning.

Heideggerian hermeneutic and interpretive phenomenology does not involve bracketing because it is not possible to bracket one's being-in-the-world. On the contrary, hermeneutics pre-supposes prior understanding on the part of the researcher (Polit and Beck, 2010). Heidegger (1962) explains:

'The projecting of the understanding has its own possibility-that of developing itself. This development of the understanding we call "interpretation". In it the understanding appropriates understandingly that which is understood by it. In interpretation, understanding does not become something different. It becomes itself...Nor is interpretation the acquiring of information about what is understood; it is rather the working-out of possibilities projected in understanding' (pp.188-189)

Hence, possibilities projected in understanding are the outcomes of interpretations. This process of interpretation is associated with the notion of the ‘hermeneutic circle’ (Crotty, 1998). The circle starts with the premise that in order to understand we need to start with ideas, *‘something we see in advance-in a fore-sight’* (Heidegger, 1962 p.191). These ideas are expressed in terms that suggest we already have an elementary understanding of what we are trying to understand, known as *‘our fore-having’* (p.191). Then *‘anything understood which is held in our fore-having and towards which we set our sights foresightedly, becomes conceptualizable through the interpretation’* (p.191). In this way, understanding becomes a development of what we have understood. Therefore, *‘...the interpretation’...whether one of...‘finality or with reservations...is grounded in something we grasp in advance – in a fore-conception’* (191). Hence, this developed understanding clarifies and enlarges the ideas that initiated the ‘hermeneutic circle’.

Gadamer (1989) a German philosopher who shared Heidegger’s interest in hermeneutics, describes the interpretative process symbolised by the hermeneutic circle, as one where the whole of a text (e.g. an interview transcript) is understood in terms of its parts and the parts in terms of the whole.

‘The anticipation of meaning in which the whole is envisaged becomes actual understanding when the parts that are determined by the whole themselves also determine this whole...This means, then, that expectation changes and that the text unifies its meaning around another expectation. Thus the movement of understanding is constantly from the whole to the part and back to the whole. ’ (p.291)

Hermeneutic phenomenology acknowledges language as a tool central to human culture, in that, it enables us to shape our understanding of experience, and ultimately our reality (Crotty, 1998). Heidegger (1962) explains:

‘Daesein expresses itself...because as Being-in-the-world it is already “outside” when it understands...Being-in and its state

of mind are...indicated in language by intonation, modulation, the tempo of talk, "the way of speaking" (p.205).

Hermeneutic focus on the meaning of language values poetry, and metaphor as a means of expressing experience by transcending the limits of language. Heidegger (1962), for example, proposes *'poetical discourse, the communication of the existential possibilities of one's state-of-mind can become an aim in itself'* (p.205).

Stanworth (2004) illustrates the use of metaphor to express meaning; in her study, terminally ill patients use metaphor as a means of expressing experience related to spirituality. She explains:

'We emerge from and return to silence, but the liminality both of human knowledge and human existence is not a 'puzzle' to be solved. It is a mystery with which we must live. Language only captures the surface of life (Ricouer 1976) and human existence carries degrees of meaning that exceed any interpretation – not as an 'add-on' but as a permeating dimension. The 'stranger' dwells in the heart of the familiar because, at life's deepest moments, something-which is no 'thing'- escapes articulation...to be concerned... with spirituality is not to be concerned with special events but akin to the artist, with the ordinary at a depth where conventional interpretations are relativized. Just as no painting is reducible to its brush strokes or any poem to the sum of its sentences...the artist's struggle to achieve ...the moment of language going beyond itself...demonstrates a fidelity to the experiences of many patients, such as...Hazel pointing to her dying flowers as mediators of 'letting go' and personal dissolution, or Arthur's 'final salute', Debbie's 'inner flame', Tracy's statue and Mary's 'golden door' are not puzzles to be solved but ingenious resorts to the 'perspectival' character of poetic language...Metaphors are miniature acts of artistic creation or poesis...' (p.210-211)

Benner (1994) has used, and promoted, Heideggerian hermeneutics, and interpretative phenomenology influenced by Heideggerian philosophy, as methodology for nurse researchers studying nurses, and nursing. Cohen and Omery (1994) believe that current descriptions of hermeneutic approaches to research have abandoned Heidegger's philosophical quest for the meaning of 'Being', and so, shifted away from ontological phenomenology. However,

Benner's (1994) view is that a hermeneutic, interpretative phenomenological research approach is ontological because the researcher is dealing with questions about why and how we know some things and not others, and what constitutes our knowing, rather than epistemological questions about what it is to know.

Benner (1994) points out that the dialogical process needed to understand and interpret texts are an extension of the researcher's pre-existing abilities to understand the world and read texts for meaning. This ability is applied with rigour and attentiveness in interpretative research. She also points out that the need to engage reasoning in particular situations, and particular texts, is an approach that is seen to come more easily to nurses with some expertise, due to, their practical knowledge about understanding and reading situations. Also, as nursing expertise evolves from experience that would include interviewing, and eliciting a person's story in a wide range of settings, they are amenable to the role of storytelling as central to an hermeneutic approach to phenomenology. Storytelling allows people to structure and give meaningfully account for what they perceived as worth noting, their concerns, and understanding of the situation. Nurse researchers phenomenological interpretation of nurses' stories of lived experience, therefore hold promise for making *'practical knowledge visible, making the knack, tact, craft and clinical knowledge inherent in expert human practices more accessible'* (p.124)

2.4c Hermeneutic-phenomenology

Van Manen (1997), a Dutch educationalist, developed an approach to phenomenological research that combines features of both descriptive and interpretative phenomenological research methodology. He describes phenomenological text as descriptive in the sense that it names something, and interpretative in the sense that it mediates between interpreted meanings and the thing toward which the interpretation points (Van Manen, 1997 p. 26). Methodological structure of hermeneutic-phenomenology comprises interplay between six research activities. The first of these is turning to a phenomenon of interest, to a particular focus on lived experience. This activity involves

explicating assumptions and pre-understandings, similar to Husserlian bracketing. However, rather than try and *'put out of play'* or *'ignore'* what they already *"know"* (p.47) researchers are directed to make explicit their assumptions and presuppositions. In coming to terms with their assumptions, researchers are then required to hold them deliberately at bay, or turn the knowledge that constitutes their assumptions against itself to expose its shallow or concealing character. The second activity requires the lived experience to be investigated, requiring re-learning to look at the world by reawakening the basic experience of the world. This reflects the Husserlian concept of turning *'to the things themselves'*. Next, a reflective grasping of what gives the experience its significance differentiates between appearance and essence, between the experience and what grounds it. Language and thoughtfulness are the means of addressing a fourth activity, one of writing and rewriting phenomenological research of an aspect of lived experience. Maintaining a strong orientation to the focus of the research and not indulging in speculations, preoccupations, or abstracting theories constitutes a fifth activity. The sixth activity addresses balance, requiring a periodic stepping back from the research to look at it as a whole, and review how each of its parts contribute to this.

2.4d Choosing the 'Best fit' Phenomenological Approach for the Study

Phenomenological reduction through bracketing or epoche is fundamental to Husserlian descriptive phenomenology. Researchers who have founded their approaches on Husserlian philosophy, for example, Merleau-Ponty and researchers of the Duquesne school of phenomenology, such as Giorgi, or those who have incorporated Husserlian phenomenology in their research approach, for example, researchers of the Utrecht School of phenomenology, such as, Van Manen, have accepted, albeit with some adaptation, the practice of bracketing to suspend, or hold at bay, preconceptions, assumptions and presuppositions, to enable attention to focus on what is essential in the phenomenon studied. However, spirituality is so central to the concept of humanity any attempt by the researcher to *'bracket out'* their personal knowledge and experience of spirituality in a study focused on this phenomenon is unrealistic. Hence, this negates the case for Husserlian

descriptive phenomenology, or the derivatives of this approach by those named above, as appropriate methodology for this study.

My familiarity with the phenomena of study has lead to my linking spirituality with loss and anticipating that this link is related to coping. Heideggerian hermeneutics, and interpretative phenomenology influenced by Heideggerian philosophy, pre-supposes prior understanding on the part of the researcher. It also acknowledges, in the concept of the hermeneutic circle, that this knowledge has brought me to study the phenomena and that my understanding is likely to be changed in the process of the study. My interest in understanding the meaning of nurses lived experience of the phenomenon of study is facilitated by hermeneutics, the interpretation of the texts of interview transcripts. Questions of how nurses know and what constitutes knowing rather, than what it is to know, make an ontological approach an appropriate methodology for this study.

Consequently the choice of ‘best fit’ phenomenological approach for a study that aims to explore nurses’ lived experience of utilizing spirituality as a means of helping patients to cope with loss associated with terminal or chronic disease, is one of an Heideggerian hermeneutic phenomenological approach.

2.5 Summary of Choice of Methodology

In summary, phenomenology as methodology suits an enquiry that is interested in the research participants’ world as they find it; that is, their experience. Spirituality is so central to the concept of person that any attempt by the researcher to fulfil the requirement of descriptive phenomenology to ‘bracket out’ their personal spirituality in a study focused on this phenomenon is unrealistic. Hence, an Heideggerian hermeneutic phenomenological approach where the researcher’s familiarity with the phenomenon is not only acknowledged, but positively contributes to shaping the research focus, is the most appropriate methodology for this study. Language is considered a tool which enables us to shape our understanding of experience. Participant stories of their experience of situations in which spirituality was a resource in coping

with loss are shared at interview and captured in textual form as interview transcripts. In interpreting these texts, the researcher's understanding of the language used elicits the meaning embodied in their 'lived experience' of spirituality as a resource in coping with loss.

2.6 Theoretical Justification for Method

2.6a Sample

Purposive sampling was used for this Heideggerian hermeneutic phenomenological study. Cohen (2000) outlines the value of purposive sampling. She emphasises the need to choose participants whose 'lived experience is likely to involve, or be impacted by the phenomena that is the subject of the study. In this way data provides in-depth information. Similarly, Morse et al (2002) advocate sampling of participants for whom the focus of study is relevant to ensure collection of optimal quality data. Sample size in phenomenological studies may therefore be small (Creswell, 2007) as optimal quality data is rich and thick enough to facilitate adequate understanding of the phenomenon studied. Benner (1994) is pragmatic in her approach to sample size, in suggesting that it is limited by the size of the transcribed text produced, in relation to the number of researcher hours available to analyse the text. She infers sufficient text provides redundancy, clarity, and confidence in the overall transcribed text, in that it will have covered an adequate range of situations. In addition, Benner (1994) explains that sample size is adjusted depending on the quality of the text, and the way the lines of enquiry are shaped by participants. Criterion sampling works well when participants sought are those who have experience of the phenomenon (Creswell, 2007). Consequently, purposive sampling for this study involved choosing specific sites where staff care for patients with chronic and terminal illness could be located, and specifying a minimum requirement of post registration practice experience for nurses to be eligible to participate.

2.6b Interviews

The phenomenologist approach to investigation of a phenomenon is purported to be one of '*openness and awe*', immersed in the here and now, consciously avoiding distraction (Finlay, 2003a p.110). Phenomenological research focuses on the participant's own perspective, and assumes that '*reality is what*

people perceive it to be' (Kvale and Brinkmann, 2009; p26). For this reason interviews are often used to access participant's lived experience. Qualitative interviews use open questions (McLaughlin, 2007). In this way participants are able to use their own words to describe their lived experience.

The purpose of interviews is to encourage dialogue to elicit participants' descriptions, perceptions, understandings and attribution of meaning to their experience (Jones and McEwen, 2002). The use of schedules, or topic guides help direct conversation toward the phenomena studied and result in interviews being designated as semi-structured. Phenomenological qualitative interviews aim to elicit meaningful data. The art of listening to explicit descriptions and meanings expressed needs to be complemented by what is said 'between the lines'. In reflecting their interpretation of what is said back to the participant in follow up questions, the interviewer is often able to ascertain the accuracy of interpretation of data (Kvale and Brinkmann, 2009).

Atkinson and Silverman (1997) consider interviews are part of common culture in that they provide a means of revealing the personal and private self, such as in television chat shows. However, they are potentially complex to administer because they involve skills of questioning, active listening, reflecting on answers and non-verbal cues as well as the skilled use of verbal and non-verbal communication to sustain participant contribution to the focus of the research study (le May and Holmes, 2012). Kvale and Brinkmann (2009) believe that conversational technique offers a style of interviewing '*that focuses on positive experiences and narratives*' (p.13). They suggest that qualitative research interviewing is a craft which if done well can be considered an art. The oral skill of interviewing is learnt through practice and the '*quality of interviewing is judged by the strength and value of knowledge produced*' (p.17). Interview knowledge is the product of the conversational relationship between interviewer and interviewee, each potentially learning from the other or the active process of interview itself. This knowledge is described as actively created by questioning and response and shaped, or, '*co-authored*' (p.54) by interviewer and research participant. Consequently,

qualitative interviewing often results in methodological decisions that need to be made as circumstances unfold during the interview itself.

Although relatively unstructured there is asymmetry of power within qualitative interviews. This is partly because the interviewer determines the focus of topics explored, but also, due to the ‘professional’ rather than ‘everyday’ nature of interview conversations (Kvale and Brinkmann, 2009). Consequently, it is important to consider the ethical implications of balancing the research interviewer’s interest in probing for further in depth knowledge against the interviewee’s interest in relation to self disclosure. Hence, the craft of interviewing includes ‘*calibrating social distances without making the subject feel like an insect under the microscope*’ (Sennett, 2004 p.38).

2.6c Reflexivity

Reflexivity relates to the researchers’ awareness of the values and experiences that they bring to qualitative study (Cresswell, 2007). It is often confused with reflection. Finlay (2003a) suggests that the terms are best considered as a continuum. She describes reflection as ‘thinking about’ something after the event, which is not dissimilar to Schon’s (1987) reflection-on-action or Johns’ (2000) reflection-on-experience involving a dialogue with self after the event. Finlay (2003a) however, describes reflexivity as involving ‘*a more immediate, continuing, dynamic and subjective self awareness*’ (p.108). This is more than Schon’s (1987) reflection-in-action, described by Johns as ‘*a kind of problem solving on the hoof*’ (p.33), but similar to Johns’ (2000) reflection-within-the-moment where self-dialogue is conscious but internalized as a response structured by reflective cues.

Finlay (2003) considers a range of perspectives in the use of reflexivity dependent on research design. These can be loosely grouped into those that use reflexivity for social critique and those that lend themselves to the ‘*more personal individual stance of ‘introspective’ phenomenological*’ researchers (p.16). Introspective reflexivity may be considered as integral to Heidegger’s concept of fore-structure (Plager, 1994), where the researcher’s familiarity with the phenomenon enables them to generate a research question related to

that phenomenon and then makes interpretation of the texts documenting relevant lived experience of the phenomenon possible. Intersubjective reflexivity is also found in the interrogating experience of interview, where a (potential) revision of fore-understanding, through a process of self-critique of assumptions, may be found to be at least partially wrong. Thus reflexivity contributes to moving thought, not merely through a circuit that feeds back on itself, as in a hermeneutic circle, but more a case of a reflexive spiral, where renewed understanding metaphorically leads to a turn in focus rather than back to a beginning (MacMillen, 2003).

Finlay (2003a) clearly and succinctly acknowledges the value of reflexivity in enabling the researcher to recognise their interpretations and ongoing revelation of the phenomenon studied in her description of reflexivity as:

'the process of continually reflecting upon our interpretations of both our experience and the phenomena being studied so as to move beyond the partiality of our previous understandings and our investment in particular research outcomes' (p.108)

However, Finlay (2003) also points out that it is the effectiveness of reflexive analysis that determines its value in research, and warns of potential pitfalls that need to be avoided. These include excessive reflexive introspection resulting in the researcher's voice overshadowing that of the participant, and in the case of reflexivity as intersubjective reflection, that overzealous *'focusing on the interpersonal process may shift attention away from the phenomena being studied'* (p.17).

2.6d Rigour

Hermeneutic philosophy considers understanding of lived human experience as contextual and therefore knowledge obtained in one situation as not necessarily the same in another. Therefore, as interviews are subject to an interpersonal context, the nuances and meanings within the context of one interview may not be comparable with another (Kvale and Brinkmann, 2009). Similarly, in relation to recordings of data gathered at interviews there are many possible readings from each transcript (MacMillan, 2003 p.248). Consequently, rather than refer to the traditional terms of reliability and

validity associated with empirical studies, qualitative studies are concerned with issues of rigour in relation to the 'dependability' or 'truthfulness' which are evidenced in the presentation of an audit trail that clearly indicates the procedural steps of the study (Jasper, 2005 p.256).

Alaszewski (2006) reviews published advice for guiding research participants completing diaries as part of empirical and naturalistic studies. Some of this advice is applicable to a diary kept by the researcher themselves 'alongside' their chosen method(s) of enquiry. Authenticity of account is critical and unsolicited entries are an excellent resource in qualitative studies. The record of reflective thoughts and feelings concerning the study in a research diary contribute to making clear any issues of process. In this way there is provision for transparency within the study to ensure that those who read it can decide if it is believable (Koch, 1996 p.178)

Although Finlay (2003a) owns she cannot claim that reflexivity ensures trustworthiness and integrity of research she is confident that it forces the researcher to stay mindfully engaged in opening up research decisions and findings to public scrutiny. Clearly situating the researcher in the study promotes transparency in indicating the potential impact that the researcher's fore-structure may have on interpretation of data.

2.6e Ethical considerations

The ethical framework underpinning healthcare practice is rooted in deontology which emphasizes professional duty (Trnabranski, 1996). However, there is a tension between this and a utilitarian view which allows societal acknowledgement of autonomy in relation to the individual's right to decide. Kvale and Brinkmann (2009) point out that these traditional ethical theories are reliant on principles and rules are not self interpreting and therefore do not determine when and how to apply the principles and rules they purport. Increasingly an alternative stance is proposed, that of virtue ethics which are more concerned with the nature of the professional involved and their perception of the situation (Mitchell, 2006). Therefore, in the research interview situation, rules and principles of traditional ethics are not

so much abandoned but are considered as guides to help with reflection on ethical dilemma. However, and most importantly, the qualitative researcher who knows her subject matter well is able to engage in moral reasoning, in that, judgment follows acknowledgment and description of events in relation to their value-laden contexts (Brinkmann and Kvale, 2005; Kvale and Brinkmann, 2009). Ethical responsibilities include academic integrity, honesty and respect for others (Punch, 2006). Ethical consideration needs to be given to arrangements concerning access to participants, self determination, autonomy and confidentiality.

2.6f Analysis

Hermeneutic analysis is by definition interpretative. Interpretative analysis is hinged on human action being considered inherently meaningful. In order to arrive at an understanding of the meaning of a particular action Schwandt (2003) proposes three ways in which we can interpret that meaning. The first of these is by empathetic identification which entails '*getting inside the head*' (p.296) of the research participant to understand their motives, beliefs, desires and thoughts regarding the phenomena being explored. Gaining such an "inside" understanding is acknowledged as central to the purpose of qualitative enquiry. The second is via phenomenological sociology where interpretative analysis is concerned with understanding how the everyday '*lifeworld*' (p.297) of the participant is constituted. Conversation, interaction and reflexivity are the means of achieving this understanding. Thirdly, language is a key to understanding significant systems of meanings, for example, cultural norms. With regard to this study empathetic understanding of each participant's lived experience of spirituality; elicited in the interaction of conversation style interviewing and reflexivity; is facilitated by my familiarity with the culture and language of nursing, the institutional norms and rules within healthcare and my knowledge and understanding of spirituality.

However, it is a fourth notion proposed by Schwandt (2003), described as philosophical hermeneutics, that is particularly relevant to a study using a Heideggarian phenomenological approach. Understanding is described as not

primarily being governed by rules or procedures, but that '*understanding is interpretation*' (p.301). Understanding requires the '*engagement*' (p.301) of our inherited bias and prejudice. In this way bias and prejudice can be examined in the throes of interaction with participants, or in the analysis of texts of transcribed interviews, and altered to further our understanding of others as well as ourselves. Understanding is always bound up with language in that preconceptions are tested in a dialogical encounter with what is not understood. Unlike other interpretative theorizing of understanding which considers that human action *has* meaning which is determinable by the interpreter, in philosophical hermeneutics the text or human action is not an '*object out there*' but '*is negotiated mutually in the act of interpretation; it is not simply discovered*' (p.302). Hence, meaning is the understanding created by the interface of perceiver knowledge with research data.

2.7 Heideggerian Phenomenology in Nursing Research

Heideggerian phenomenological philosophy and methodology have been considered in relation to the subject of study. However, as the focus of the study involves gaining an understanding of nurses' lived experience of spirituality, the final section of this chapter explores the use of Heideggerian phenomenology in nursing research.

Phenomenological methodology is particularly helpful in research that considers aspects of the art of nursing, revealing the nature of human experience (van der Zalm and Bergum, 2000), particularly of illness, rather than merely a biophysiological focus on disease (Benner, 1985; McBean, 1991). The focus of this study is one that hopes to elicit the meaning in and understanding of nurses' lived experience in relation to specific situations in their everyday practice, to capture the '*nuances in shifting importance and rapidly changing relevance that can be recognized by human beings in a situation*' (Benner, 1985 p.7). Although not the methodology of choice for predictive theory, the understanding that emerges from phenomenological enquiry has sensitizing or anticipatory abilities (van derZalm and Bergum, 2000), which if shared in the wider context of the profession may increase

practitioners awareness of the nuances of care that are so easily neglected in a culture dominated by objective measures of effectiveness.

The use of Heideggerian methodology has become increasingly popular among nursing researchers (Draucker, 1999). However, this has resulted in critique of the way in which hermeneutic phenomenology is interpreted and applied in nursing research. Crotty (1996), for example, critiques Benner's work involving a Heideggerian approach as more humanistic in its interpretation than Heideggerian.

A dilemma raised by Horrocks (2000) is the tendency for nurse researchers to move on from Heideggerian consideration of the ontological, a focus on 'Being', to the ontical, a focus on the activities of beings, that were not actually considered by Heidegger, but are attributed to manifestations of his work. This is perhaps understandable given that research outcomes are so often ultimately concerned with improving nursing action that constitutes professional practice.

Heideggerian research involves the individual as an inclusive part of reality in that they are '*immersed in the world*' (Larkin et al, 2006 p.105) that they inhabit. Heidegger uses the term *Dasien* to characterize the nature of human-beings, which is to be there, '*always somewhere, always located and always amidst and involved with some kind of meaningful context*' (p.106). The Heideggerian view of the person is therefore always one of a 'person-in-context.'

It is on this aspect of Heideggerian phenomenology that Paley (1998) is also critical of nurse researchers. He believes that they misinterpret methodological implications of Heideggerian phenomenology by tending to focus on the 'lived experience' of a group of respondents, who share a common situation or predicament. In this way nurse researchers stray from a Heideggerian focus on the lived experience of a 'person-in-context' to one of concern exclusively with the question 'what is this or that kind of experience like?' (p.820). He

suggests that this tendency reverts to the Cartesian tradition of considering the conscious self as 'outside' the world that this self or subject observes, a view Heideggerian philosophy rejects. Both Paley (1998) and Horrocks (2000) attribute misinterpretation of Heideggerian phenomenology to nurse researchers' tendency to read Heidegger through other authors.

However, as Horrocks (2000) explains Heidegger considered 'Being' more important than questions about beings and therefore bypassed epistemological study of beings in favour of the more primordial ontological study of Being. The consequent challenge for researchers is that *'it is difficult to find a way through him...back to reason, knowledge production (epistemology) and hence method'* (Rennie, 1999 p.6).

Draucker (1999)'s critique takes a different stance and is more focused on rigour. She advises that nursing studies need to provide a more transparent description of the processes involved in interpretative research, including a stronger acknowledgement of how the researchers' personal experiences, values and beliefs impact hermeneutic studies. Such a recommendation affirms the value of nurses maintaining a research journal to give account of reflective thought, reflexivity and clarity of process in phenomenological research.

Clearly, it is important to acknowledge and address, as far as possible, the issues raised in such robust critique. However, as Ashworth (2003) points out, the perceptual orientation of the Heideggerian approach to hermeneutic phenomenology is also alive to the socially constructed nature of experience (p.23). It offers an appropriate philosophy for this study, which is, focused on gaining an understanding of nurses' perceptions of the way they understand and use spirituality to help them care for patients facing the challenges inherent in advanced chronic or terminal illness. Van Manen (2002b) suggests Heideggerian methodology can evoke understandings of discretionary, intuitive and tactful capacities. In this way this study uncovers knowledge embedded in nursing practice by using a methodology that follows the Heideggerian 'tradition' of hermeneutic phenomenology. Hence, the sequence

of Chapters recording the process and outcome of this study reflects this tradition with the next Chapter addressing the fore-structure of understanding that has lead me to research spirituality, prior to consideration of the method of collection or data analysis.

2.8 Research Journal

Occasionally, when I first started this study I felt as if the focus of my research was becoming increasingly distant. This was largely due to the reading and exploration of research paradigms and methodology that ultimately enabled me to justify my choice of approach for research. This rather delayed any sense of getting on with ‘doing’ research. Intensely theoretical in nature and inevitably including copious new terms this period tested perseverance. However, it was also a time of significant growth in understanding and ‘insightful moments’ brought such a sense of achievement when I had made a real link between my exploration and future desired destination I triumphantly recorded these in my research diary. These short notes were not really reflective but more a collection of ‘memos’ that Birks et al (2008) describe as appropriate to all qualitative research. The following examples reveal insights that contributed to the decision making process in choice of methodology.

Intuitively comfortable with writing I found Van Manen’s (2006) affirmations empowering. He asserts the link between writing and emergence of insight, that such textual material possesses hermeneutic and interpretative significance and in citing Heidegger (1982) suggests that ‘*genuine phenomenological method consists in creating one’s path, not in following a path*’ (p.720). I had previously noted how daunted I was by negative critique of nursing theorist’s interpretation of Heideggarian phenomenology for what was claimed to be a humanist approach and wondered if there was a ‘purist’ form of this methodology. Therefore, I found the proposition that ‘creating one’s path’ was authentic phenomenology liberating!

Similarly, I noted the value of reflective account as a means of making visible the vision and stance of the researcher as the way to ground the study in my

own subjective reality (Jasper, 2005). The transition from memos to reflection became increasingly important as my theoretical exploration moved into the practicalities of data collection. Together my notes and diary became my research journal.

2.9 Summary

An Heideggerian hermeneutic phenomenological approach has been justified as the most appropriate methodology for a study that is interested in nurses' lived experience of spirituality as a resource in coping with loss. Theoretical justification is then given for the use of a purposive sample and semi structured interviews as the primary source of data collection. Reflexive awareness of the values and experience brought to a qualitative study enables the researcher to recognise their interpretations of data through self-critique, and in this way develop enhanced or amended understandings of the subject of study. Reflective thoughts recorded in a research diary provide a measure of the 'dependability' or 'truthfulness' of the study in accounting for issues of process. Interpretative analysis rests on the belief that human action is inherently meaningful. Empathetic identification with the participant, understanding of how their everyday '*lifeworld*' is constituted, together with, their use of language as key to understanding cultural norms, are ways in which the meaning of experience described by participants can be interpreted. The ethical responsibilities of the researcher are also outlined. Finally, some consideration has been given to the use and critique of Heideggerian hermeneutic phenomenology in nursing research.

Chapter 3

Fore-structure of Understanding

3.1 Introduction

Chapter 2 has outlined how Heideggerian philosophy is centred on the *'situatedness of human being-in-the-world'* (Plager 1994, p.69). Being situated in the world allows the researcher a background and familiarity that is shared with all humanity. In addition, it allows an individual interpretation of the world that has evolved from personal history and culture. In this way the researcher comes to an Heideggerian hermeneutic phenomenological approach to research with a fore-structure of understanding. The Heideggerian concept of fore-structure is described by Plager (1994) as being threefold. The first of these is that of fore-having, which is related to the researcher's familiarity with the phenomena that is the subject of study, and so makes an interpretation possible. The second is fore-sight described as the point of view generated by the researcher's background from which an interpretation is made, and lastly, fore-conception where the researcher's experience may contribute to some anticipated expectation of interpretation.

Familiarity may result in aspects of understanding being taken for granted and therefore the researcher may lose sight of how fore-structure affects their interpretation of, and reflexive response to, research participants' disclosure. Therefore it is important that a reflection on fore-structure precedes data collection to counteract any such oversight. An account of fore-structure also enhances transparency of the research process, and so strengthens the credibility and ethical standing of the study.

Fore-structure constitutes part of Heidegger's hermeneutic circle of understanding which has been considered in more detail as part of this study's methodology (Chapter 2). The limited literature review that follows particularly reflects my fore-having, that is, my familiarity with the phenomena of spirituality. This is explored within a number of themes, the first of which is the impact of loss on personal identity. Also, my understanding of spirituality as an aspect of being a person is considered, as is differentiation between spirituality and religion. The themes of meaning and

purpose in life, forgiveness, relationship and hope are addressed in terms of spiritual need. The final theme gives some account of the cultural perspective of spirituality. This initial literature review also accounts for the remaining facets of fore-structure in reflecting my fore-sight, in linking spirituality with loss in health care contexts, and my fore-conception, in anticipating that this link is related to coping. A second literature review was conducted following the analysis of interview data and integrated into the discussion of study findings.

3.2 Impact of loss on personal identity

Chronic or terminal illness can undermine an individual's sense of identity. Whether abrupt or insidious in onset, the longstanding duration of illness that is managed, rather than cured, means that the chronically and terminally ill may benefit from support in facing the consequent challenges of their conditions. A greater understanding of the processes used by nurses to help patients make sense of their situation could potentially enable nurses to facilitate the most effective support for those in their care.

Neimeyer (1997), a Professor of psychology, well published in issues of chronic loss associated with dying and death uses case studies to illustrate a valid critique of traditional theories, and their descriptive stages of adaptation to loss. He proposes an alternative understanding, a constructivist approach founded on the assumption that reconstructing a world of meaning is central to the experience of grieving. The personal reality of loss is individual and not universal, it involves actively facing the challenges of loss rather than remaining passive. Personal meanings, not only of the loss itself, but also in relation to emotional, behavioural and physical responses provide a holistic portrayal of adaptation to loss rather than the more traditional focus on emotional reaction. In this way significant loss is seen to transform an individual's world rather than lead to the recovery of a previous norm. Interestingly, Parkes' (1996) studies from a psychiatric perspective of grief in adult life, first published in 1972, reflect what is currently regarded as traditional theory, describing a model of grief constituting four phases; shock, searching, despair and then adjustment. However, this is a rather narrow

interpretation of his work on bereavement given that he describes not only potential alarm and anger as a trauma response to loss, and searching as a grief response but also psycho-social transition as a process of adaptation to change which involves the adoption of a new model of the world. Parkes (1971) draws together ideas from research on stress, loss and crisis studies to propose psycho-social transition as a new conceptual field. This concept is still included in contemporary published work (Parkes, 2000) and although using different terminology appears to have much in common with Neimeyer's (1997) perspective above. Fundamentally, they convey the sense of us each creating an assumptive world by organising who we are, our identities, as we go along and make sense of the self and world by creating personal interpretations of our experiences. Consequently, when circumstances involving significant and permanent loss shake this sense of self and world, we try to interpret events in ways consistent with our identity and the ways in which we have understood past experience. In caring for those with terminal and chronic illness nurses share an interface with significant and cumulative losses by others that may challenge their own assumptive world. Involvement with patients who struggle with their sense of identity in the face of life-changing events may trigger existential questioning by nurses which results in a shift in their assumptive world. Raising the question 'why?' often reflects a search for existential meaning within particular life events that happen during the course of work. Such questioning is at the heart of what is meant by the term 'spiritual' (Speck, 1992).

3.3 Spirituality as an integral aspect of every person

Historically, in Western society, nursing care was delivered within religious orders (McGilloway, 1985). Every person was thought to have a spiritual potential, an awareness of, and relationship with God that they would look to, in order *'to find some sense in their suffering; to be assured of some enduring value in themselves...and above all to find some meaning in their existence'* (Pett, 1973: 405). Attempts to move towards provision of secular care resulted in a fall in standards, for example, the provision for the sick within the Elizabethan poor laws. The enlightenment moved eighteenth century society towards secularization, and persons were viewed more analytically as being

comprised of body, mind and spirit rather than an indivisible whole. By the nineteenth century a rising population and changes in medical knowledge meant that religious orders could no longer cope with the provision of nursing (Baly, 1980). Florence Nightingale's middle class status gave the role of the nurse, normally considered unpleasant, a new respectability, providing the humanist philanthropist with a vocation previously associated with the religious. Nightingale did not require that nurses necessarily practice a religion, but her selection was based on Judeo-Christian ethics and morals, in that, "character" was of vital importance (Widerquist, 1992). Nightingale's model of nursing embraced the humanity of persons in being 'covenantal' (Bradshaw, 1994), in that, nursing involved experiential knowing, often shared non-verbally within the nurse-patient relationship. Nursing action based on these shared moments unfolds as a transformative act that honours the art of nursing, and the nurses' personal commitment to care (Clements and Averill, 2006). However, the secularisation of nursing continued, registration and moves towards professionalisation as the twentieth century progressed moved nursing into contractual care, in line with task accomplishment values of an industrialised society (Stuart et al, 1989). While medical treatment of persons' physical disease gathered kudos, psychiatric care of persons' disease of the mind was '*relegated to some sort of second place*' (McGilloway, 1985 p.75) and the spiritual care of persons was difficult to find, and at best, something for the attention of chaplains and '*people like that*' (p.75).

The later part of the twentieth century saw a revival of interest in covenantal models of care, particularly in the work of Cicely Saunders (1976) at St Christopher's Hospice where the concept of caring for the whole person, or holistic care, reinvigorated an interest in the spiritual needs of persons, as well as managing their physical, social and psychological needs. Increasingly, nursing' professional and statutory bodies have formally affirmed the significance of spirituality. The Royal College of Nursing (1993), for example, has described spirituality as an integral aspect of the whole person. Similarly, it is increasingly featured in national health policy guidelines, for example, both the Department of Health (2003) and the National Institute for

Clinical Excellence (2004) acknowledged spiritual care as important within service provision.

Spirituality is a complex concept. Bradshaw (1996) exemplifies this in her critique of the Royal College's standard on palliative nursing related to spiritual support. She challenges the implied dualism of spiritual care as a separate topic of care and prefers to describe spiritual care in nursing as an attempt to '*establish the nature of humanity*' (p.42). Her concern is that academic account of this concept is piecemeal and used to justify clinical care rather than help nursing engage with the complexities of humanity. She proposes that spiritual care should not be the self-conscious delivery of an additional aspect of care but that compassionate care of the person is in itself the expression of spiritual care. However, the theologian Henri Nouwen (1981) explains how compassion competes with our desire to 'do' something in the face of suffering:

'Let us not underestimate how hard it is to listen and to be compassionate. Compassion is hard because it requires the inner disposition to go with others to the place where they are weak, vulnerable, lonely and broken. But this is not our spontaneous response to suffering. What we desire most is to do away with suffering by fleeing from it or finding a quick cure for it. As busy, active, relevant people, we want to earn our bread by making a real contribution. This means first and foremost doing something to show that our presence makes a difference. And so we ignore our greatest gift, which is our ability to be there, to listen and enter into solidarity with those who suffer' (p.34)

Regardless of debate, both health policy and contemporary models of nursing care agree that all persons have a spiritual dimension. Hence, spiritual care needs to be addressed for the agnostic or atheist as well as for those with a religious affiliation (Burnard, 1993).

Comprehensive review of published literature and research demonstrates that spirituality cannot be conveyed in a single definition (Greenstreet, 1999; Greenstreet, 2006c). Some emphasise the qualitative benefit of fulfilment in the transcendent nature of spirituality as an essential part of wholeness, rather than entire dependence on the everyday world of the material (O'Brien, 1982;

Hover-Kramer, 1989). Others, such as Burkhardt (1989) found on analysis of case studies what she described as an ‘unfolding mystery’ equated with the renewal that emerged following hardship or suffering. This renewal was sourced from an inner strength associated with inward reflection, supportive relationships, a sense of knowing self, closeness to nature and with a ‘higher’ being, all of which contributed to a feeling of harmony. This inner strength is reflected in the writings of the philosophical theologian, Paul Tillich (1947, 1953) whose perspective on spirituality encouraged ‘God’ to be seen, as the depth or ground of all being, rather than ‘reducing God to ‘a’ being alongside other beings’ (Thistleton, 1988 p.688; Harrison and Burnard, 1993). In this way, Tillich argued, if ‘God’ is depth, there can be no non-believers unless someone can seriously say that life is superficial. This argument further affirms the spiritual dimension of all humanity, but it is in the individual’s definition of ‘God’ that the true key to understanding spirituality is to be found. This is exemplified in Scherer’s (2006) description of spirituality in popular culture, where the rituals and symbols among sports supporters display characteristics of a ‘secular’ religion (p.89, p.94) outside of any understanding of ‘God’ as conceived by Tillich.

Burnard (1988) points out that people cannot simply be divided into ‘believers’ and ‘unbelievers’, because fundamentally many people give little thought to spiritual issues. Writing as a nurse educationalist he goes on to emphasise the importance of nurses clarifying their own belief and value systems before they are able to help patients with existential or ‘ultimate’ questions. Similarly, findings of a large scale empirical study concerning spiritual pain at the end of life, that invited questionnaire responses from Flemish speaking palliative care health workers, (and so included nurses), also advocated a greater awareness among caregivers of their own spiritual experiences (Cornette, 1997). The reason given for this is summarized in the following:

‘Caring for the spirit implies, primarily, caring for oneself. It relies on the ability to stay with all that is vulnerable and weak in the other – and in oneself. Otherwise we start projecting our ideas, our needs, our pain into another’s story (Cornette, 1997 p.13).

3.4 Differentiating between religion and spirituality

Sheldrake (1991) explores the history of the term spirituality. Seated in Christian religion, the term seeks to express the conscious human response to God that is both personal and ecclesial, or *'life in the spirit'* (p.37). He outlines changes in the meaning of spirituality that have emerged in Western Christianity in the later part of the twentieth century. These include the suggestion that spirituality is not exclusive to any *'one Christian tradition, nor even necessarily with Christianity as a whole'* (p.50). Also, spirituality is not so much about perfection, but more to do with surveying the complexity of *'human growth in the context of a living relationship with the Absolute'* (p.50). In addition, spirituality is not limited to a concern with the interior life *'but seeks an integration of all aspects of human life and experience'* (p.50). The broadening use of this term has contributed to its current relevance to, and use in, non-religious contexts.

Bradshaw's (1994) research concerning the spiritual dimension is an exercise in concept analysis and clarification which utilises theology, (as elucidatory together with critical reasoning to interpret this concept), and then philosophy (using rational analysis of how things appear to be, to understand reality, truth and meaning), as methodology rather than either of the more conventional qualitative or quantitative approaches. The study analysis is comprehensive, but as McFarlane (1994) points out this research is a difficult read as it draws heavily on philosophical and theological vocabularies. Bradshaw (1994) writes of how those freed from self-preoccupation by their knowledge of God's love were enabled *'into fruitfulness for others'* (p.11) as an instrument of the love by which they themselves lived. This perspective reflects the historical roots of nursing as a religious vocation. The emphasis was on spiritual rather than physical care; support rather than cure. It is therefore not surprising that spirituality has often mistakenly been equated with religion by nurses.

However, Cicely Saunders (1988), a nurse, almoner and physician and the founder of the modern hospice movement, was very clear in her differentiation between the two concepts:

'Spiritual' surely covers much more than the religious. It is the whole area of thought concerning moral values throughout life. Memories of defections and burdens of guilt may not be seen at all in religious terms and hardly be reachable by the services, sacraments, and symbols that can be so releasing to the 'religious group' (p.30)

Heriot (1992) reviewed literature and research concerned with spirituality and ageing. She also differentiates between religion and spirituality and in doing so brings many of the dimensions of spirituality together. Spirituality is described as a broader notion, an umbrella under which religion and the needs of human spirit are found. Spirituality is described as being concerned with the personal interpretation of life and the inner resources of people, whereas religion is seen as an external, formal system of beliefs. Therefore, although spirituality is not synonymous with religion, for those who have a faith, religion is one means of fulfilling spiritual need.

A descriptive survey of cancer patients' spiritual coping strategies by Sodestrom and Martinson (1987) found that the majority of patients exercised religious faith through spiritual activities, such as praying, as one means of coping. Later research by Fehring et al (1997) also found that religion was a means of coping for cancer patients, but their findings were more discerning in accounting for why religion helped. In their descriptive correlation and comparative study they differentiated between those patients who took their religion seriously and practiced their faith as part of their daily lives, and those who participated in religious practice as a means of sociability, security or solace. The former are described as intrinsically religious and their faith provided psychic strength, meaning, purpose and transcendence as ways of coping. The latter, are described as extrinsically religious and draw on their religious group for social support to help them cope.

In her review of nursing literature that scanned twenty six years Emblem's (1992) analysis found six words repeatedly appeared in definitions of religion.

The definition that results from collating these describes religion as a *person's organised system of beliefs, practices and form of worship* (41). Consequently, for nurses who can relate to these systems, their religion may constitute a personal resource in helping them to cope with caring for the terminally or chronically ill. Religion may provide answers to existential questions of meaning related to the circumstances they find themselves in or perhaps provide solace within a supportive social network. Similarly, nurses who do not have a religious faith may still draw on their own personal interpretation of life that constitutes their source of strength when faced with such questions, or their social network when needing solace.

3.5 Spiritual needs

Following a review of palliative literature Kellehear (2000) defines spiritual need as seeking and finding meaning, transcending hardship and suffering. This is supported by wider reviews of published literature (Greenstreet 1999, 2006c) where common themes of meaning and purpose, the need for fulfilling relationships, hope and forgiveness emerge as spiritual needs, all of which are reflected in Kellehear's (2000) theoretical model of spiritual needs in palliative care.

3.5a Meaning and purpose in life

The search for life's meaning and purpose and the significance of existence are frequently discussed in literature describing spirituality (e.g. Martsof and Mickley, 1998; Narayanasamy, 2004). McColl (2000) describes the relationship between spirituality and meaning as reciprocal in that spirituality invests activities with meaning and meaningful activities express spirituality. The religious believer may understand the meaning and purpose of life as a mission, the source and taskmaster of this mission being God (Fish and Shelley, 1978). The meaning and purpose of life for non-believers may be a career, family, money or even self (Oldnall, 1996; Harrison and Burnard, 1993). Frankl's (1984) observation and experience of suffering in Nazi concentration camps resulted in his belief that an important determinant of survival of difficult circumstances is a sense of meaning and purpose in life that transcends the immediate situation.

Caring for others who are struggling to find meaning in their situations of loss demands 'personal vigilance' by nurses. Wakefield (2000) describes a case study of a patient she had nursed to illustrate nurses' inclination to protect themselves from the distress associated with a dying patient. She points out the inevitable sense of loss and that '*relentless self-care*' (p.245) needs to be an important feature of end of life care nursing. The suggested means of achieving this is to act out the advice given to bereaved relatives. This involves the nurse saying goodbye to the dead person before they leave the ward as a form of social closure of caring interaction. Other suggestions involved sharing feelings through stories, reflection, and debriefing, as well as asking any questions that may help them contextualise and make sense of events. In this way, nurses 'personal vigilance' maintains their own emotional and spiritual capacity to deal with patients' and their relatives' losses (Kinghorn and Duncan, 2005).

3.5b Forgiveness

Stanworth (2002) describes spirituality as more easily recognised than explained. Using metaphor she describes the spiritual dimension as a horizon, '*further, broader and even more ungraspable than...any other*' (p.192). In glimpsing this ultimate horizon the foreground is not changed, but its meaning can be radically altered. She goes on to explain that in the same way, past events can not be altered but can be seen in a fresh light, and this change is the experience of forgiveness. In end of life care situations, guilt due to a sense of failing to live up to expectations, can be a cause of spiritual distress (Narayanasamy, 2001). Attentive nurses may recognize the nature of this distress and facilitate the means for patients to achieve a need to forgive or be forgiven.

McCullough et al (2003) propose that forgiveness involves constructive psychological change toward a transgression and that this change takes time. The ways in which individuals appraise transgressions impact their ability to forgive (McCullough et al, 2006). Attributional theorists emphasise the influence of the degree of responsibility or blame attributed for the

transgression, as opposed to interdependence theorists who emphasise the role of relationship commitment. Others emphasise the effect of empathic emotions that stimulate helping behaviour, due to, for example, a desire to restore a breached relationship. Following their own study McCullough et al (2006) propose an additional aptitude that facilitates forgiveness. The study sample was large involving 213 women and 91 men representing a variety of cultural and ethnic backgrounds. Participants were undergraduates and hence the mean age was low at just over 19 years. Participants completed an initial questionnaire identifying an occasion when they had been hurt or offended, and a final questionnaire about their current feelings related to this event, but in between they completed a writing task where one third wrote about the benefits that had come out of this event, one third about the traumatic features and the remaining third wrote about a topic other than the event. McCullough et al (2006) found that the ability to focus on the benefits gained from a transgression, such as, realization of personal inner strength or renewed spirituality, helps negate some of the psychological costs, such as, loss of trust, and so enables forgiveness.

Clearly, the mean age of patients in end of life situations exceeds that of participants in McCullough et al's (2006) study, but the principle that the way in which individuals appraise transgressions impact their ability to forgive does provide face validity for these findings in end of life care situations, particularly as findings corroborate published comment that describes practice experience or exemplifies patients thoughts, such as Saunders (1995) and Stanworth (2006) below. Given that, unforgiveness is itself a cause of stress due to the nature of emotions generated, the ability to replace negative emotions, such as anger, with positive emotions, such as empathy, means forgiveness provides a means of coping (Davis et al, 2009). The capacity to forgive oneself, to shift emotional appraisal from negative to positive, or as Myco (1985) suggests, to live with one's '*flaws*' (p.44) is clearly reflected in the experience of Cicely Saunders' (1995) work with dying patients:

'There is a progression from trust in the acceptance by others of all the things in ourselves that we regret into a faith in forgiveness, where we at last believe that they have no more

power to hurt us or anyone else. We cannot alter what has happened or what we have done, but we can come to believe that the meaning of the past can be changed. From this comes an ability to forgive ourselves. This may never be expressed in words on either side but the quality of the ensuing peace is unmistakable' (p. 55)

The following excerpt from Stanworth's (2006) study illustrates Saunders (1995) point. In it a middle aged woman who was paralysed by motor neurone disease describes how her feelings of guilt are disappearing and identifies the changes and benefits that her personal tragedy has brought:

'I used to feel guilty for being divorced twice and a failure, but these feelings are going rapidly. Being ill has fit things into perspective for me. You can see the sense of freedom in my poems. I've had to lose myself to myself. I've had to learn to love people for what they are and not to compartmentalize; not to put anyone's worth in terms of their status. At last I am stepping out of an unhappy place into freedom to develop my own feelings and attitudes. My hope is that it (the illness) will lead me into peaceful waters, sailing on a calm sea. I have expended so much anger in the past and have longed to be rid of it. It seems that this tragedy has taken me on this path at last' (p.33)

A search for meaning is often evidenced by existential questioning asking "why"? There is often no known answer to existential questions that patients pose and consequently nurses should not burden themselves with guilt when they are unable to respond or understand.

3.5c Relationships

The third theme is acknowledging the importance of relationships, whether with others, a transcendent power or the natural environment. The nature of love given and received within relationships is seen to differ. Literature suggests human love is conditional, dependent on 'if' the other satisfies a

need, or 'because' of what the other has, who they are and what they are (Lewis, 1971; Fish and Shelley, 1978), or, dependent on the attractive qualities of others (Bradshaw 1994). This is contrasted with unconditional love usually associated with a 'higher power' or God. Unconditional love is described in various ways, as a gift, selfless, gracious, undemanding (Lewis, 1971), self giving love (Bradshaw, 1994).

However, Campbell (1984) proposes a theology of professional care in which he refers to professionals having the potential to give 'moderated' love which is unconditional. This moderated love appears synonymous with Nightingale's (1859) view of care as covenantal, being concerned as much with 'how' care is given as with what is 'done' (Greenstreet, 2007). The relationship between patient and nurse in covenantal care is one of 'mutual sharing' freely given as part of 'personal commitment' (Bradshaw, 1994, p.4). Campbell (1984) describes the sharing of self in a professional context in order to enhance care as an example of self-transcendence.

The terminally and chronically ill may well have long term health care needs that result in nurses coming to know their patients and their carers very well. The challenge for professionals in sharing self is that they risk suffering grief following the loss of those they care for. A study by McIntyre (2002), that involved interviewing sixteen nursing staff from eight wards, exemplified how nurses 'grieve too' when they care for the dying and their relatives. An earlier study by Davies and O'Berle's (1990) involved comparative analysis of data derived from in-depth retrospective descriptions of the care given by a supportive care nurse to ten palliative care patients and their relatives. They found that valuing the inherent worth of others, and in particular, of individual patients she came to know was a key concept related to the nurse as a person, as was preserving her own integrity. The latter was achieved partly by the nurse's ability to maintain feelings of self-worth and self-esteem by periodic reflection on meaning in relation to the work she was doing, feedback from others that contributed to her feeling that she made a difference, continual self-assessment of whether she was doing the right things for the right reason, and acknowledging and accepting her own feelings, including those of grief.

In addition integrity was maintained by maintaining energy levels by setting limits, using strategies of distancing to regain control, using humour, hiding personal feelings, learning from mistakes and sharing frustrations. Although focused on a single nurse's experiences, this study hones in on the vital issue of nurses needing to maintain integrity if they are to continue to help end of life care patients and their families. It is also of value in providing illustrative examples of how this may be achieved.

3.5d Hope

The concept of hope is an integral aspect of human spirituality and constitutes a fourth theme. It concerns a sense of future and is described by Bauckham and Hart, (1999) as:

'...a vital function of imagination lying at the heart of our humanity. Specifically, it is the capacity to imagine otherwise, to transcend the boundaries of the present in a quest for something more, something better, than the present affords.' (p.72)

Desroche (1979) describes the miracle of hope as a rope. In myth, a rope is thrown in the air, anchored in cloud, and carries the weight of the man that climbs it. Thus is the nature of hope, remaining intangible and eluding explanation in an era of scientific reason, and yet clung to in life's most difficult moments (Greenstreet and Fiddian, 2006).

Nurses may have difficulty in conveying hope in an extremely disabling disorder such as motor neurone disease (MacLeod and Carter, 1999) or appear pessimistic to avoid giving false hope (Faulkner and Maquire, 1994). They may, therefore benefit from a better understanding of this concept (Greenstreet, 2006b). There are a number of studies available that explore hope. These potentially raise nurses' awareness of strategies that may enhance hope, both for themselves and those they care for in practice, for instance, an American study by Herth (1990). This used a convenience sample of thirty terminally ill adults accessing support from three hospices, each patient having a prognosis of six months or less. Patient semi-structured interviews, together with responses to a hope index tool, and background information allowed triangulation of cross-sectional data. In addition ten patients were

interviewed and completed the hope index tool on two further occasions, when impairment of their ability to complete activities of daily living became severe, and then, when signs and symptoms indicated that they were likely to die within two weeks. This allowed triangulation of longitudinal data. Extraordinarily, the published account of this research makes no mention of the ethical significance of repeated access to participants who are dying, in utilizing their 'time left' to live, neither does it acknowledge the changing nature of end stage illness in relation to participants' ability to continue to contribute. The study was replicated in England by Buckley and Herth (2004) and on this occasion ethical considerations were acknowledged. This second study supported the findings of the first in that hope remained present despite nearness to death, as well as corroborating that interpersonal connectedness, spiritual base, attainable aims, affirmation of worth, lightheartedness, personal attributes and uplifting memories, all provided ways in which hope could be fostered.

These studies provide a potentially useful guide in maintaining and inspiring hope in those needing to focus particularly on 'being' in the present moment. The strategies work on the premise that giving up on particular hopes does not mean giving up on hope altogether (Greenstreet and Fiddian, 2006). They are as beneficial for the nurse as their patient in that they help nurses locate hope in caring for the terminally ill in facilitating a 'good' death by:

'...getting to know the patients as individuals, treating the family as the unit of care, allowing patients and family to express their needs and preferences, then exercise control over events during their care.' (Seale, 1989; p.553)

Interpersonal connectedness is one means of fostering hope and is described by Buckley and Herth (2004) as comprising meaningful relationships, of being loved and giving love. Acknowledging the universal nature of hope may be the first step in enabling professional carers to make interpersonal connections with those in their care. Having a sense of something that is important to all humanity could provide some common ground on which to start building a therapeutic relationship. The study by Davies and Oberle (1990) illustrates

that a nurse providing supportive and palliative care ‘globally’ valued the inherent worth of others regardless of individual characteristics and then in connecting with the patient and family, developing a rapport and establishing trust, she came to value the patient and family in a more ‘particular’, individualised way. Similarly, in her study which considered nursing interventions for engendering hope in the chronically and terminally ill, Herth (1995) found that connectedness was rated highly by professionals.

Uplifting memories also fostered hope, in having a temporal dimension, the patient’s past is reflected on in the present and contributes to hope in its association with the future. Relationships that are open to sharing these moments of reflection provide opportunities to affirm mutual worth. Buckley and Herth (2004) found patients shared good memories that seemed to be important to hope. They found attitudes of staff important in helping patients remain hopeful. Patients particularly valued the ‘little things’ that staff ‘bothered’ to find out for them. Similarly, hope was fostered by personal attributes or characteristics such as, optimism and cheerfulness, which if nurtured, provide opportunity for lightheartedness. Spontaneity, sensitivity in the use of humour and the ability to laugh as the moment dictates create joyous moments for both patient and professional that can contribute to sustaining hope (Herth, 1990; Buckley and Herth, 2004).

In Morse and Doberneck’s (1995) qualitative study describing the concept of hope, interview data was gathered from four participant groups, which included patients with chronic illness (heart disease) and disability (spinal cord injury). Concept analysis was thorough, starting with identification of processes or characteristics of hope, (abstract components), from a single account that provided the best example illustrating hope. These abstract components represented a tentative framework constituting the concept. Choosing the ‘best example account’ initially appears to be subject to researcher bias, however, this choice is ‘tested’ by finding examples of identified components of hope in other accounts. If this search proved fruitless, the original characteristics were wrong and the process was repeated using another example account. Finally, data from each group interviewed

was compared component by component. Findings identified seven attributes, or components that collectively made a markedly goal-orientated description of the concept of hope:

'Hope is a response to a threat that results in the setting of a desired goal; the awareness of the cost of not achieving the goal; the planning to make the goal a reality, the assessment, selection, and use of all internal and external resources and supports that will assist in achieving the goal; and the re-evaluation and revision of the plan while enduring, working, and striving to reach the desired goal' (p.284).

Some findings in this study were similar to those of Buckley and Herth (2004), for example, in relation to hope and relationships. Morse and Doberneck (1995) found that the attainment of a goal is not achieved alone but includes the solicitation of mutually supportive relationships. These relationships are balanced and so it is rare for all members to have doubts about the feasibility of a goal at the same time. Support strategies used in these relationships may be 'hands-on' support or indirect support that bolsters the individual's ability to deal with their situation, for example, affirming personal attributes such as courage or endurance (Penrod and Morse, 1997). Nurses are party to these mutually supportive relationships.

3.6 Spirituality and culture

Spirituality reflects sociocultural values (Sheldrake, 1991). Different cultures vary in their philosophical stances. The Western Transcendent view of spirituality, which supports the concept of a reality beyond the material world, contrasts with the Eastern Pantheism which views the world as a single entity, spirituality being synonymous with the forces of nature (Bradshaw, 1994). Similarly, in the West spirit is localised in time and place within individual consciousness, as that part concerned with ultimate awareness, meaning, value and purpose (O'Rawe Amenta, 1997). Whereas, in the East the emphasis is on spirit as a non-local quality, timeless, space-less and an immortal element that links humanity with the environment and ultimately the universe (Heliker, 1992).

Garner (1987) considers the secularization of Western societies as culturally in-built, in that there is a refusal to believe that God can be heard and consequently, no steps are taken to hear. Jarvis (1993) sees the absence of metaphysical or supernatural belief, together with an inability by many to understand the complexities of science and technology as constituting socio-cultural systems that contribute to a void in contemporary society, a lack of meaning in our material world. However, as a result of society's loss of meaning, Tacey (2004) describes a counter-cultural revolution, one of spirituality that finds the sacred everywhere, a direct political and philosophical challenge to traditional notions of sacredness, such as, the body, nature, the feminine and the physical environment.

Heelas and Woodhead (2005), describe the 'subjective turn' as a major cultural shift from '*life lived in terms of "objective" roles, duties and obligations*' to '*life lived by reference to one's own subjective (relational and individualistic) experiences*' (p.2). The goal of this cultural shift is therefore '*not to defer to higher authority, but to have the courage to become one's own authority*' (p.4). Postmodern individualism is certainly reflected in the shift from professional paternalism to increasing autonomy for those accessing healthcare services (Greenstreet, 2007). The language of the subjective turn is used by Heelas and Woodhead (2005) to distinguish between religion and spirituality, religion subordinates life to a "*higher*" *authority of transcendent meaning*' whereas the subjective-life cultivates the '*unique*' and the '*sacred*' (p.5) within. Their research considered religion and spirituality in a town in North East England. The primary aim was to establish the numerical significance of 'alternative spirituality' or 'the holistic milieu' taking place outside broader institutional contexts such as hospitals. Results reflected unequivocal evidence of growth in alternative spirituality, which, in their study, constituted complementary and alternative medicine.

However, contemporary discourse on nursing spirituality in a secularized society can potentially create greater confusion rather than further clarity (Greenstreet, 2007). Heelas (2006), later goes on to make a theoretical argument that equates nursing spirituality with complementary and alternative

therapy, described as 'holistic spirituality'. Nurses as members of contemporary society, share the values and beliefs of the culture in which they have been educated, live and work. It is not unreasonable to support the view that the increased interest in complementary and alternative medicine is reflected among nurses, but not necessarily in their contracts of employment. However, they may be involved in the practice of referral of patients to alternative and complementary therapists as part of health care provision. It is important that the myth sourced from nursing's religious roots, equating spirituality with religious belief and practice, is not replaced with a new myth, sourced from nurses' current secular cultural roots, that spirituality equates with a belief in complementary and alternative medical practice (Greenstreet, 2007 p.96). There are a number of significant differences between Heelas' (2006) theoretical account of holistic spirituality and nursing research and literature that addresses spirituality as a perspective of holistic care. Comparison of these discourses demonstrates that 'spirituality as a perspective of holistic care' is a more comprehensive discourse, within which 'holistic spirituality', as described by Heelas (2006), reflects an option for providing spiritual care (Greenstreet, 2007).

McGrath (1998) suggests that we do not have limitless possibilities of ways to act, or an infinite number of theories concerning existence, and that culture is the template that outlines what the possibilities are. She also describes the medical model of care as a cultural system that nurses are very familiar with, emphasising disease and fact over experience and belief. Hence, this tends to limit nurses to an approach that reduces care to a concern with task and function. McGrath (1998) proposes that conceptualising illness as a problem of meaning is an alternative approach that offers a way of understanding the role of culture in framing behaviour and belief. In this way McGrath (1998) links cultural and spiritual care and encourages professionals to reflect on the ways they approach and respond to patients with chronic and terminal illness. Nurses, therefore, need to consider their own beliefs and behaviours around terminal and chronic illness as well as their skills in sensitive questioning and active listening. Although it is important for nurses to continue 'doing' care for those with physical and pathological disorders, McGrath's suggestion

encourages nurses to consider their style of approach to patients, 'how' they are with those in their care.

Using an inductive approach to open systems theory and social ecology, Friedemann (1995) developed a framework of systemic organization to serve as a theoretical basis for family nursing. Although I am unfamiliar with this inductive approach the theoretical framework that evolved, when later applied to nursing the spirit (Friedemann et al, 2002), is useful in conveying an understanding of a number of emotions and behaviours displayed by patients and their relatives in end of life care situations. Hence, face validity can be attributed to the outcome of Friedemann's (1995) work when applied in these contexts. Friedemann (1995) claims, that the ideal condition of all systems is one of 'congruence', but as all systems are subject to change and conflicting values, congruence is never reached. The consequent tension created by incongruence is experienced as anxiety. Friedemann et al (2002) link culture to the way in which individuals manage the anxiety that results from a change in health status. They believe that humans are equipped to buffer the effect of the tension that such changes bring by balancing control in their lives with spirituality. The ideal balance is individually determined depending on the emphasis that culture, beliefs and values place on either control or spirituality. In a Western culture which predominantly values control, individuals tend to strive to re- establish pre-existing conditions. This involves deliberate behavioural strategies such as seeking medical treatment for illnesses. Nurses are involved in both the care and treatment of illness, for example, in the administration of prescribed medication. Control is not always possible. The sense of loss of control may result in a variety of emotions on the patient or relative's part, such as anxiety, anger and resentment. These emotions may be directed at nurses at a time when professional carers are also coping with similar emotions in facing their own inability to control the outcome of care. This is illustrated by the following response from a nurse participating in McIntyre's (2002) study:

'A few weeks ago we had a young 24-year-old in the ward. That was the most difficult thing I have ever had to deal with in my whole career. It was hard watching her mother and her two brothers suffer. I couldn't switch myself from that.' (p.113).

The struggle for control is individual, familial and societal. Friedemann et al (2002) suggest an increased emphasis on spirituality allows a more philosophical approach which facilitates transcending the immediate situation and so helps in acceptance of the limits of human control on the natural order of events. Hence, spirituality as an alternative resource to control provides a defence against anxiety and is particularly appropriate where change, such as terminal or chronic illness, is not reversible. Similarly, spirituality may allow the nurses to transcend their immediate environment, to see their situation within a wider universal order that is outside the artificial limits of control. In this way, nurses may be less anxious and possibly better able to deliver supportive care.

3.7 Summary

My introductory chapter, together with this account of fore-structure of understanding, provides an overview of the knowledge and experience that has brought me to this study's particular focus on spirituality as a resource in coping with loss. Publications that have been the product of my scholarship in both spirituality and loss are referenced and provide evidence of comprehensive literature search in both subjects as a constituent element of my knowledge.

The purpose of my account of fore-structure of understanding from a phenomenological perspective is one of transparency, to reflect a subjective self awareness that acknowledges that what I know impacts how I interpret participant descriptions of their experience. This reflexivity allows critique of assumptions I have made and an awareness of how they are changed in the throes of interview or on analysis of interview transcripts. Conscious self awareness is promoted further by my keeping an account of my reflective thoughts throughout the study, but particularly in relation to data collection and analysis. In this way keeping a reflective diary provided a valuable tool in contributing to a transparent account of the research process, and hence, strengthened the credibility of the study.

My knowledge and experience have illuminated how elusive defining spirituality is and how difficult this concept is to describe. It is both covert, in constituting the core of self, and overt, reflected in the way we live, in what we do and how we 'are' with others. Published literature and policy guidelines imply that spirituality is a resource for coping with loss, but offer little understanding in identifying how nurses use spirituality to help them care for patients facing life threatening illness. This study addresses these issues.

Chapter 4

Method

4.1 Introduction

The methodology for this research is justified in Chapter 2. A qualitative study that follows an Heideggerian hermeneutic phenomenological approach appeared to best suit the task in hand. The choice of method of data collection must always be one that provides data that addresses the study aim and objectives. Kvale and Brinkmann (2009) describe the purpose of semi-structured life world interviews as obtaining descriptions of the lived experience '*of the interviewee in order to interpret the meaning of the described phenomena*' (p.3). Hence, this style of interview was particularly suited to collecting data for this study. Also, the researcher, embedded in their social world (Finlay, 2003) cannot avoid being caught in the construction of 'sense-making' and so it is that a hermeneutic approach to phenomenology acknowledges the researcher's own language, culture, history and consciousness of the phenomenon studied. Hermeneutic phenomenological research is therefore a joint product of the researcher, and researched, with the researcher's knowledge both impacted 'in the action of the interview' with the participant as well as 'in interpretative reflection on' the transcript of the research participants data following interview. This in part is what is meant by the term '*reflexivity*' (Ashworth, 2003 p.15). This chapter will therefore consider the sample, the conducting of semi-structured interviews and the use of a research journal documenting observed process, as well as the ethical considerations necessary for data collection. The intended approach to data analysis and the means of establishing the rigour of the study are also considered. The aim and objectives of the study are outlined below.

4.2 Aim

This study aims to explore nurses' lived experience of utilising spirituality as a means of helping patients to cope with loss associated with terminal, or chronic disease.

4.3 Objectives

- To gain an understanding of nurses' perceptions of spirituality as an aspect of person centred care.
- To explore the extent to which nurses facilitate spirituality as a source of coping.
- To explore how nurses use their personal resources in caring for those with chronic and terminal conditions.

4.4 Sample

Data collection was through a purposive sample. In this case the group constituted nurses involved with end of life care in hospice, community, and care home settings within South East England who were willing to participate. In this way the sample reflected some heterogeneity in practice context (Bryman, 2012). Exclusion criteria included acute settings, practice contexts where patient throughput is rapid, and nurses working outside South East England.

Access to a hospice, care home and community primary care trust was negotiated within the same geographical area. Permission to carry out the study was sought from the senior nursing manager of each clinical context. Registered nurses with at least three years experience in practice were invited to participate in a semi-structured interview. In this sense the sample was homogeneous in relation to professional group (Bryman, 2012).

The purpose of the interviews was not to explain, predict or generate theory, but to understand shared meanings by drawing from participants a picture of their lived experience of spirituality in relation to situations of loss, complete with the richness of detail and context that shaped their experience (Sorrell and Redmond, 1995). The particularly focused nature of the study rendered it likely to support a small sample size (Bryman, 2012). The interviews progressed alongside concurrent thematic analysis of meaningful patterns of the lived experience of spirituality in relation to situations of loss, illuminated in the texts of interview transcripts. Concurrent analysis helped determine sample size by reflecting sufficiency of overall transcript text in evidencing

clarity, and confidence that an adequate range of situations had been covered (Benner, 1994).

In total twelve nurses were interviewed. Guest et al's (2006) found that twelve interviews sufficed for most researchers who aim to discern themes concerning common views and experiences among a relatively homogenous group. Five interviews were conducted with nurses employed within a hospice and three further interviews conducted with nurses employed in a nursing home. Unfortunately, there were no participants from the selected community setting. Consequently, following permission from the local Trust's Research and Governance Coordinator, (Appendix 1b) the managers of two further community practices were approached to seek their support in inviting their staff to participate in this study. Both managers agreed with this proposal although no interest in participating in the study was expressed by nurses from one community setting. However, four interviews were conducted with nurses employed in the other community setting. Consequently, the sample heterogeneity in relation to practice context was inclusive in its sub-group variability (Bryman, 2012). This contributed to adequacy in relation to the range of situations covered (Benner, 1994).

4.5 Conducting the semi-structured interviews

In order to encourage dialogue to elicit participants' descriptions (Jones and McEwan, 2002) before commencing each interview I emphasised that the nature of the interview would be more like a conversation rather than me asking a lot of questions. I also pointed out that I anticipated that the participant would do most of the talking because I was interested in their thoughts and experiences around the topics we were going to consider.

I tried to reduce the potential impact of the more 'professional' context of interview rather than 'everyday' nature of conversation (Kvale and Brinkman, 2009) by using Field's (1989) style of explaining to participants that there were no right or wrong answers and that they could share their thoughts and experiences as they perceived them, but sometimes I would ask further questions to clarify or seek expansion on something they had mentioned.

Kahn (2000) notes that traditional phenomenology uses a broad opening question that focuses on the phenomena under study. To this end, a topic guide (Appendix 2) was used to help direct conversation toward the subjects of spirituality, loss and personal resources. This guidance of the direction of conversation accounts for the 'semi-structured' nature of interview sessions. I found reflecting back my understanding of what participants had said, as suggested by Kvale and Brickman, (2009), particularly from their earlier comment in the interview, was a useful source of clarification both for me and for the participant, and a means of developing responses, for example:

'I think you implied...that your life experience has contributed to your understandings of spirituality...Has anything else contributed to your understandings of spirituality?' (1)

'You've given...one example at least where you sensed the patient had a spiritual agenda...Are there other examples from practice...?' (1)

In order to conduct semi-structured interviews, arrangements were made to see each participant individually for a period of at least one hour. The interviews lasted between an hour and an hour and a half. Participants were all sent written information, prior to consenting to interview, which explained that these events would be recorded on audio-tape for later transcription. This provided a fuller record of the dialogue during the interview than written notes could provide, however, some notes were still taken during the interviews to record participants' non-verbal behaviour and also to avoid interrupting the participant by noting issues mentioned that I was interested in following up. Notes were also made of the context in which the interview took place and incidents that impacted the flow of response, for example, tannoy announcements during the interviews at the nursing home. To maintain rigour of research process, audio tape recordings were independently transcribed (Appendix 3 is an example). Transcripts were then audited against original audio tape recordings (Tuckett, 2005).

Also, to enable awareness of other factors that may impact responses at interview participants were asked to complete a brief questionnaire to provide information regarding age, gender, professional qualifications, posts held since qualification as a registered nurse and any relevant post registration training or education that they had undergone (Appendix 4).

4.6 Research journal

Entries into my research diary were dated and made as soon as possible after any events related to data collection, including both interviews and review of transcripts. In this way it was possible to 'capture' my thoughts before they were lost or my feelings before they faded and thus 'retrospection bias' was minimized (Alaszewski, 2006 p.113). Together my diary entries and notes constituted my research journal. The following is a summary of my journal reflections on the process and rationale for decisions regarding method.

4.6a Arranging interviews

Following the initial invitation for nurses to participate in the study I was pleased by several early responses from both nursing home and hospice nurses. However, a number of postponements due to participants needing to change shift, attend to family commitments or recover from ill health soon made me realise that I would need patience in my endeavours to access participants for interview. Gradually, the number of Hospice and Nursing Home interviews completed grew, although a very harsh winter caused further delay because of staff shortages and hazardous travelling conditions.

I had no response from any community based nurses. On reflection the reasons for this were numerous. I had met and spoken with the senior community manager regarding permission to access staff a year before commencement of interviews. She had determined which community team was most appropriate for me to approach for participants given the nature of my study and informed the relevant community matron. Reorganisation of community staffing meant the senior manager was no longer in post when I commenced interviewing, but the community matron who had been informed of my research and my permission to approach her staff was still in post. In the two other practice settings involved in my study I had had the opportunity

to meet each of the Hospice and Nursing Home managers in person to explain the nature of my study and answer any queries they had. They were also very keen to use my flyer and positively 'market' my need of participants interested in taking part. Unfortunately, I was never able to meet the community matron. She was also very difficult to catch at her desk for a telephone conversation and used e-mail as her main mode of communication. When I did establish contact with her she was about to go on holiday for a number of weeks but 'left the poster for staff'. I did not receive any enquiries or expressions of interest of participation from this team.

After completing the necessary arrangements to extend my study into other localities of the Primary Health Care Trust with the local Research Network Management and Governance Co-ordinator (Appendix 1b) I was able to approach other community managers. Fortunately, one very enthusiastic community team leader positively 'marketed' my study. This resulted in a series of interviews with community nurses, although once again these were delayed due to adverse weather conditions and increased demands on the community nursing staff.

My experience of arranging interviews with nurses in practice highlighted how crucial the interest of managers is in raising awareness of their staff of the option to participate in the study, and so facilitate researcher access to the participants.

4.6b Environment

I arranged interviews to take place in the familiarity of their workplace environments in the hope that nurses taking part would be 'more themselves'. I really appreciated clinical and service managers' support in achieving this. These arrangements were also beneficial to participants both in relation to time and financially in not having to travel to another venue.

My awareness of the pressure on use of quiet space in work environments was increased in interviewing across the different participant practice sites. Hospice had a number of spaces that I used to interview which were overall

quiet and the one occasion of noise from staff in an adjoining office was easily managed by interviewing on the opposite side of the room. The upper floor environments were made more comfortable by the use of air conditioning when interviews took place at the height of summer.

All interviews at the nursing home took place in the same room which was well away from the clinical environment. However, the interviews were interrupted by intermittent tannoy announcements and screaming sirens from the nearby motorway. The level of noise on these occasions meant verbal communication had to cease, but then, appeared to continue in a very 'British' style as if nothing had ever happened!

The community interviews were in some ways the most disrupted. The first interview was interrupted by a member of staff reminding the interviewee of her next meeting and hence seemed to impacted the ambience to one of 'must finish'. The second interview had to cease and recommence in a different room mid way because a visiting professional interrupted the interview and explained she had booked the room for the rest of the afternoon. After relocating we were interrupted again by the doctor whose room we were using, but he was very obliging and left us to continue. He put his head to the door during the third interview, obviously in the hope of accessing his room but did not enter, although his computer had been left on and continually emitted a significant drone throughout my use of the room as a reminder he anticipated returning! Fortunately, participants were familiar with their environments and I do not think these interruptions impacted the quality of interview data.

4.6c Collecting biographical details

I had purposefully planned to present the questionnaire concerning biographical details prior to commencing each interview, rather than send to each participant with information about the research beforehand. This was to avoid putting participants off with a questionnaire to complete that required additional personal time, to ensure they did not have to remember to bring anything to interview, and generally, to facilitate a good return of completed

questionnaires. However, I was a little naïve in anticipating the impact of this plan on the interview itself. This became apparent in my very first interviews which were with very experienced staff who had a long professional history that took them a little time to try and remember how long they were in each post they had held, and when this was! My first interviewee had trained and practiced in her own country as well as for many years in the United Kingdom. She was quite taken aback that she might have to try and recall all of this information and I suggested that she note down, perhaps, at least the previous past five years experience. My second interviewee had arranged a meeting with a manager exactly one hour after we met, but after starting the questionnaire she arranged to delay this meeting so she was able to complete all details fully. I felt at this point that the biographical questionnaire generated a rather unsettled start to the actual interview situation, but fortunately each participant had a wealth of experience to share and we soon settled into a better ambience for thoughtfulness and conversation. My next few interviewees had less history and provided good practice for me to deal with this activity effectively without generating concern in participants while I set up and checked my recording equipment.

Only participant 9 failed to complete the section on past experience and again I think this was a time factor. She was an experienced senior member of staff who had arrived a few minutes late and took the questionnaire with the intent of completing it later, probably to compensate for time lost. Her partially completed questionnaire was returned to me by a member of her team before I left the practice establishment. On reflection, this affirmed the value of providing space for completion of the questionnaire prior to interview because I was available to clarify when participants had any queries regarding the questionnaire and responses completed in this way were overall quite comprehensive.

4.6d Impact of acquaintance

I have had a specialist interest in creation and delivery of palliative care education for more than ten years and therefore I was not surprised to find that I was already acquainted with a number of the interview participants as

previous programme students, or that they remembered me from a palliative module that they had attended. During some interviews I thought participants were very palliative focused in their responses and wondered if this was due to association. Some of the participants who already knew me appeared a little uncomfortable in the initial stages of the interview, perhaps due to the contrived nature of the meeting in comparison with our previous encounters, but this did not last long. Also, because I shared nursing as a common professional background with participants, and a number had previous dealings with me as an educationalist, I made a point of explaining that in the context of the interview I was in research mode before we began the interview. Interestingly it was me who strayed into nurse mode on one occasion, but I acknowledged this within the interview.

4.6e Transcripts

My experience of conducting qualitative research interviews was limited and therefore my first transcript was reviewed before proceeding. In this way I could assess my interview skills and determine which aspects of my performance could be improved to facilitate accessing best quality data. The transcript lacked any inference of non-verbal communication and affirmed the significance of keeping notes regarding this aspect of the encounter. I found reviewing the transcript while listening to the interview audiotape valuable in affirming the accuracy both of transcribing and notes of non verbal communication taken.

At times I had been aware of my hesitancy in questioning during the first interview but I was surprised to find how many ‘incomplete’ sentences I used in conversation, as did the interviewee. I had reflected back effectively in the interview but in the later part of the session had begun to direct questioning rather than facilitate conversation as I had intended. I did ‘check out’ that my understanding of what I had heard was correct on occasion but some of my questions seem to meander a little, and others appeared rather leading, so there was room for improvement!

Following this review I made some adjustments to how I introduced ideas for discussion, for example, rather than ‘in your experience’ I found using ‘what do you think’ produced a more responsive outcome. I also spent a little more time ‘setting the scene’ with participants before turning the tape on. I thought Field’s (1989) style of introducing a qualitative interview might help and so, before commencing recording, said something like:

‘Basically what I am doing is talking to nurses about their thoughts on spirituality and loss in relation to people with chronic illness or who are terminally ill. You can be as frank as you like – there are no right or wrong answers – what is said is anonymised so I will not mention your name while recording. I’ll ask you some general questions and let you talk as much as you want – I probably won’t say very much just let you talk’.

4.7 Ethical considerations in collection and storage of data

Research interviews involve human interaction that affects interviewees and the knowledge produced potentially affects understanding of humanity. Therefore, interviewing for research has significant ethical and moral implications (Kvale and Brinkmann, 2009). Theoretical perspectives of research ethics are considered in Chapter 2, p29-30. The inclusion of National Health Service staff as potential participants in the study meant that mandatory approval of the local Research Ethics Committee was sought prior to commencement of interviews (Appendix 1a).

Written permission to access nurses employed in designated institutions and primary care trust was sought from appropriate managers. Staff were invited to participate in semi-structured interviews and provided with written information outlining the study (Appendix 5). Participants were assured of the anonymity and confidentiality of data collected in the explanatory letter and again at interview. Written consent was gained from all participants and participation in interviews was voluntary (Appendix 6). Interviews were conducted in an environment conducive to privacy, the site of which was negotiated with the participant and/or their manager. Participants had the right to withdraw from interview if they so wished, however, no participant chose to do so. Sources of staff support were identified in case recollection related to accounts given at interview caused upset. Sources of support included clinical

supervision or counselling. To ensure security of data, records that hold the names of participants have been kept separate from data that links participants to codes. Hard copies of interview transcripts have been kept in a locked filing cabinet to which only I have the key. Electronic records of transcripts are held on a password-protected computer. Research participants were reassured that the transcripts of interviews would not include any identifying features. In this way when I come to disseminate details of the data I have collected and my conclusions in published work or at professional conferences anonymity of participants will be maintained.

4.8 Data Analysis

Clarke (1999) refers to qualitative analysis as an intuitive personal journey for the researcher in which meanings ‘emerge’ from the data as themes and categories. However, the dilemma of following a Heideggerian tradition of hermeneutic phenomenological research is that, as outlined in Chapter 2, Heidegger’s focus on ‘Being’ rather than questions about ‘beings’, his focus on ontological study rather than knowledge production results in a lack of specificity of method, in this instance, of approaching thematic analysis (Horrocks, 2000; Rennie, 1999). Hence, a tool to address the process of analysis was sought. A stepped approach to analysis, closely reflecting the scheme of Smith et al (2009) was chosen. This facilitated a methodical approach to engaging with and interpreting the meaning of the ‘lived experience’ documented in the transcripts of semi-structured interviews with the participants. The documentation of each step, for each text, clearly demonstrated process in interpretation and consequently contributes to evidence of the rigour of the study. This process started by looking at one transcript, and then moving on to the others one by one. Emergent themes were listed and analysed to elicit connections between them. Full details of this process are explained in Chapter 5.

4.9 Rigour

A researcher’s self-conscious awareness of the values and experience they bring to their research contributes to rigour, in that, staying mindfully engaged in opening up research decisions and findings to public scrutiny reflects a transparency of process that promotes trustworthiness (Finlay, 2003a). My

account of the relevant knowledge and experience that I brought to this study was initiated in its introduction in chapter 1, continued in my account of fore-structure in Chapter 3, and maintained by my recording day to day thoughts and feelings, generated, for example, at interview encounters or on reading interview transcripts, in my research diary. Such information was helpful in providing insight into how situations were interpreted and made sense of (Alaszewski 2006). Notes outlining my relationship with participants and any other influences that impacted research decisions helped maintain my awareness of personal subjectivity (Jootun et al, 2009) in interpretation of meaning of these factors, and so, contributed to a transparent account of critical analysis and interpretation of data. These reflections and notes collectively constituted my research journal. A summary of journal data that illustrates process and rationale for decisions regarding method is included in 4.6 above. Journal data that related to analysis is included in 5.3.

Chapter 5

Data Analysis

5.1 Introduction

This chapter addresses the process of analysis of data collected. The stepped process used for formal analysis of data is described, although an initial, informal analysis of data started at the point of conducting the interviews. Such a '*beginning of sorts*' (Cohen et al, 2000 p.71) is inevitable in phenomenological studies where interpretation of meaning begins on hearing the data at interview.

This self-conscious awareness of researcher engagement impacting the data, or reflexivity, is also considered within this chapter. My reflective diary and notes that together comprised a research journal have provided an ordered account of my experience of making sense of research activities throughout this study (Riessman, 1993), and here are used to enrich the account of process in relation to the analysis of interview transcripts (section 5.3)

5.2 Analysis of transcripts of interview data

The intention of the analysis was to try to understand participants' experiences of spirituality as a resource for coping with loss. Reflective engagement with the interview data, recorded as text in transcripts, enables the researcher to give an account of what they think the research participant is thinking, known as the double hermeneutic (Brogen, 2010). In this way, although findings in an Heideggerian hermeneutic phenomenological approach to research aim to be accurate, they are somewhat tentative (Kahn, 2000a). Repeated, or iterative, engagement with each transcript, allowing a shift from looking closely at a small piece of one text to seeing this in the context of the whole of that particular text, and vice versa, demonstrates the metaphor of the hermeneutic circle in guiding interpretation (Cohen et al. 2000). Similarly, individual texts are understood in relation to all texts and vice versa (2.4b).

The rationale for choosing a stepped approach to analysis, closely reflecting the scheme of Smith et al (2009), is given in 4.8.

5.2a Step 1

The first step in formally commencing data analysis involved reading and re-reading the transcript. The audiotapes of all interviews were independently transcribed and the accuracy of transcription was checked by listening to the appropriate audiotape while reading the transcript. Repeated listening to a recording triggered not only the recall of the voice of the participant which was sustained during subsequent readings of the transcript, but also recall of the whole scenario of the interview ambience itself. Reliving the event in this way, together with repeatedly revisiting a transcript allowed an increasing familiarity with the text which Cohen et al (2000) describe as '*immersing oneself in the data*' (p.76).

5.2b Step 2

The second step of analysis was one of initial noting. A wide margin was made on the right hand side of each page of every transcript. Exploratory comments were noted in the margin during the readings of the transcript (Appendix 7a). Initially, these were descriptive in nature identifying key words, phrases or explanations given by the participant that reflected their thoughts and experiences related to loss and spirituality. These comments embodied their experiences in relation to 'their world' and comprised thoughts not only on their current professional practice experience, but also, for many, additional comment on their past professional practice and/or their personal life experience.

Listening to audiotape recording of an interview while reading the transcript also provided the opportunity to note the manner of the participant's response against what was heard on the recording, such as laughter, sighs and thoughtful pauses. In this way linguistic comment was added (in italics) to exploratory comment and initiated a focus on the way language was used by the participant (Appendix 7b). In looking closely at small pieces of text it was possible to see what Smith et al (2009) point out, that at times, the way language was used and the content are clearly interrelated, an example was when research participant 10 was '*choked*' when describing her emotional response to a card left by a patient. Similarly, Heidegger (1962) considered

intonation and modulation in the use of language, the tempo of talk, “*the way of speaking*” (p.205) as Daesin expressing itself, Being-in-the-world and its state of mind (2.4b). Metaphor could also be identified in this way and provided a means of conveying a strength of feeling, or the scale of an experience, for example, when participant 2 described the impact of her son’s suicide by saying, it ‘*threw my world just up in the air and it came crashing down in bits and pieces*’, she communicated some sense of the challenge that coping with this magnitude of loss presented. Most participants were inclined to be thoughtful in addressing the issues posed in their interview encounter. This was evident by pauses, before, or in the throes of their response. Similarly, humour was used by all respondents at some time during their interview, often paradoxically when describing difficulty or having difficulty in describing an experience.

Notes in my research diary also consider the impression of ‘whole’ interview style and reflect that overall, participants varied largely in the way they used language. Such paralinguistic properties of speech are important in conveying either, emotion, or a nuance of meaning not evident in the text of transcripts, or affirmation of the interpretation of meaning and emotion conveyed in the text (Nygaard and Lunders, 2002), such as the illustration above of participant 10 being ‘*choked*’.

Participant 1 tended to be hesitant in her use of language and on occasion would reiterate a question to herself before answering, for instance, ‘*Right, what is the soul?*’ She also questioned herself as if trying to find a response, for example, ‘*So, what shall I...? Right*’. I attributed this hesitancy to the fact that she was Dutch and therefore was working at expressing concepts that are in any case difficult to verbalise, in English as her second language.

In contrast participant 2 was eloquent and confident in her responses, as was participant 4. They had both been registered nurses for more than forty years and so had a significant experience of practice, but it was in their comprehensive account of loss or illness suffered in their personal life which

particularly conveyed their confidence in understanding what had shaped the development of their own spiritual growth and coping mechanisms.

Participants 7 and 11 were rather serious in their expression. Early in her interview participant 7 expressed the concern that '*I'm not explaining this very well*' and participant 11 that she wasn't going to be '*very useful*'. I felt as if both were being rather conscientious in wanting to 'get it right'.

Participants 3 and 8 tended to use humour more frequently than the group as a whole, although in very different ways. Participant 3 used laughter frequently in an almost raucous manner and on occasion finished with a sigh. This felt rather cynical as if there was another agenda she was not sharing. Participant 8's use of humour felt open and sincere, for example, laughing at his own paradoxical interpretation of the benefits of religion, and also laughing at his own understanding of one patient's communication as contradictory.

Participant 12's demeanour and tone reflected her claim of '*I'm sort of struggling a bit*' when it came to describing specific practice examples to illustrate general comments she had made. Her difficulty could be attributed to her being one of the youngest participants and in that sense having less lived experience in practice to draw on. Participant 11, the youngest respondent had a similar struggle.

Following on from comment on use of language, the transcript was revisited to add further comment, this time focused on trying to capture the research participant's overarching understanding of matters of loss and spirituality in that context. These comments were added to those in the right hand margin but were underlined to differentiate them from descriptive notes of participant responses (Appendix 7c). Smith et al (2009) describe this activity as one of conceptual comment requiring the researcher to be more interpretative and so begin to move away from explicit participant comment to '*conceptual annotating*' (p.88). Reflection produced tentative ideas or questions, and so opened up '*provisional meanings*' (p.89). There was a natural tendency for me

to draw on my own experience and professional knowledge in framing these thoughts.

5.2c Step 3

Step three of the process of analysis involved the development of emergent themes. The data now constituted interview transcript text and exploratory comment or notes. This third stage required a shift to primarily dealing with the analysis of exploratory notes rather than directly with transcript text. In this way the quantity of detail was reduced but the quality of complexity of data was maintained by the integral link between exploratory notes and transcript. Analysis was focused on a piece of text and related notes rather than the 'whole' transcript and so on 'parts' of data. These parts were ultimately reconfigured to form a new 'whole' as emergent themes were grouped later in the analysis. Themes are terms or phrases which succinctly embody the essence of the piece of transcript and reflect both the participant's words and my interpretation of them (Smith et al, 2009). Emerging themes were noted in the left hand margin of the transcript alongside illustrative excerpts of text (Appendix 7d).

5.2d Step 4

Searching for connections across emergent themes constituted step four of the process of analysis. Abstraction is one means of achieving this and involves identifying patterns between emergent themes, '*putting like with like*' (Smith et al, 2009 p.96). In this way themes were grouped into a smaller number of super-ordinate themes. Each super-ordinate theme was given a title that reflected the overarching focus of constituent themes. Then every super-ordinate theme was designated a different colour so that illustrative theme excerpts could be colour coded in the transcript (Appendix 7e). The colours designated to super-ordinate themes are reflected in Table 5.1.

5.2e Step 5

Step five of the process of analysis involved moving on to the next transcript. If new themes emerged as each transcript was analysed these were recorded as before or existent themes strengthened by additional illustrative excerpts. Ultimately themes were not being further enriched by any new comment.

Therefore, twelve interviews reflected sufficiency of overall transcript text and included an adequate range of situations across practice contexts (Benner, 1994).

Following the analysis of these twelve interview transcripts emergent themes had been grouped into five super-ordinate themes, details of which are illustrated in Table 5.1 below.

Table 5.1: Super-ordinate and clustered themes

Super-ordinate theme Colour coded in transcripts	Themes emerging from data
Loss as a spectrum	Dominant issues of loss Consequences of loss for patients and their significant others Impact of loss on nurses
Belief as the pillar of spirituality	Meaning and purpose Religious and non-religious faith Faith as a resource to 'regulate distress' Personal philosophy as a coping strategy
Being a spiritual carer	Rapport and relationship as a spiritual resource Replenishment
Becoming proficient in spiritual care	Facilitation of religious practice as a spiritual resource Empowerment of patients Empowerment of support staff Personal loss; a source of enhanced understanding and positive growth
Belonging as the means of maintaining spiritual integrity	Accessing support for patient care Informal support for nurses Formal support for nurses

5.2f Step 6

Step six involved looking for patterns across participants' data. As the study sample constituted twelve participants it falls into Smith et al's (2009) large sample category. They suggest an important facet of large sample analysis is accounting for a measure of what is meant by recurrence of a super-ordinate theme across participant data and advise recurrence should be specified and illustrated. Table 5.2 below illustrates recurrence of super-ordinate themes. The transcript page number and colour coding of the illustrative excerpts for super-ordinate themes are given for each participant.

In specifying recurrence, two super-ordinate themes, loss as a spectrum, and belonging as the means of maintaining spiritual integrity, were 100% recurrent in all participant interviews, in that, all interviewees manifested the same super-ordinate theme in different emergent themes. Recurrence was approximately 92% evident for both the super-ordinate theme, belief as the pillar of spirituality, as only participant 11 did not describe any experience of the constituent emergent themes, and the super-ordinate theme, being a spiritual carer, as only participant 3 did not describe any experience of the constituent and emergent themes. Similarly, recurrence was 83% evident for the super-ordinate theme, becoming proficient in spiritual care, as participants 7 and 8 did not describe any experience of the constituent emergent themes.

5.2g Step 7

In addition to the six steps advocated in Smith et al's (2009) scheme I added a further measure that might be considered another step. Step 6 of this analysis tool promoted a quantitative style, numerical measure of illustrative quotes. The reduction of participant account to numerical data divorced it of meaning and added nothing to findings. Steps 1-5, on the other hand, effectively promoted the teasing out of qualitative account which embraced nuance of meaning and addressed the aim and objectives of the study. Hence, the study findings presented in Chapter 6 represent the outcome of a 5 stepped approach to analysis. Step 7 therefore constituted a value judgement that resulted in the decision to use a 5 stepped approach to analysis, rather than the full 6 steps advocated in Smith et al's (2009) scheme.

Table 5.2 Identifying incidence of recurrent themes

Super-ordinate Theme	Themes Illustrative excerpts in blue in transcript	Participant number and transcript page in blue											
		1	2	3	4	5	6	7	8	9	10	11	12
Loss as a spectrum	Dominant issues of loss		10 5	12 11 13	16	14	7	7		10			
	Consequences of loss for patients and their significant others	12 11				14	2 3	11	14 15	10	6 7	7	5 9
	Impact of loss on nurses	13		20	27	19				17	9 11 15		4

Super-ordinate Theme	Themes Illustrative excerpts in red in transcript	Participant number and transcript page in red											
		1	2	3	4	5	6	7	8	9	10	11	12
Belief as the pillar of spirituality	Meaning and purpose			1	18 19	1			18 16				1
	Religious and non-religious faith	2 7 10			3	1	1 6	2	1 2	1	1		
	Faith as a resource to 'regulate distress'		2 9			2	6	16	16 18	17	16 17		7 6 11
	Personal philosophy as a coping strategy						13 14	14		16	12		

Table 5.2 Identifying incidence of recurrent themes (continued)

Super-ordinate Theme	Themes Illustrative excerpts in green in transcript	Participant number and transcript page in green											
		1	2	3	4	5	6	7	8	9	10	11	12
Being a “spiritual carer”	Rapport and relationship as a spiritual resource	15 5 14	11		3	4		3	7 10 11	4 18	4 3	3 6 4 9	7
	Replenishment	16	19			18	4	16	20 19 21		14 15		12 11

Super-ordinate Theme	Themes Illustrative excerpts in orange in transcript	Participant number and transcript page in orange											
		1	2	3	4	5	6	7	8	9	10	11	12
Becoming proficient in spiritual care	Facilitation of religious practice as a spiritual resource	6 7	1	8 26	1 14 13	13				5 6	1	5	3
	Empowerment of patients	19	16			16	9				8 13		
	Empowerment of support staff			16 17	24	5 6							
	Personal loss; as a source of enhanced understanding and positive growth		6 7 1							8			

Table 5.2 Identifying incidence of recurrent themes (continued)

Super-ordinate Theme	Themes Illustrative excerpts in plum in transcript	Participant number and transcript page in plum											
		1	2	3	4	5	6	7	8	9	10	11	12
Belonging as the means of maintaining spiritual integrity	Accessing support for patient care	10	20 13	2 3 14	17	8 13 17		5	8	11 14 15			
	Informal support for nurses	17	18	22		7 9	12	15	17	19	14	10	11
	Formal support for nurses	17	23	22		18	4 5 11						

5.3 Research journal

Reflections on the process and content of participant interviews were recorded in my research journal and are themed and included below.

5.3a Cause for thought

The interview process gave almost all participants cause for thought to the extent they appeared thoughtful, or moved or appeared near tears at some point in the session. My response to these emotional moments varied. At times I found myself acknowledging my understanding of the difficulty of the situation they were describing, or that what they were saying was very moving, almost as an intuitive form of reassurance that it was alright for them to share such emotions in the interview. However, on other occasions, it felt more supportive for me to remain silent and leave space for them to accommodate how they felt. By the time I had completed the first three interviews my appreciation for participants contributing to my research developed into a sense of privilege regarding what they were prepared to share with me. All participants had shared something very personal that they had not or would not normally share.

The first participant appeared very quiet/thoughtful and a little ‘flat’ after the tape was turned off. In checking she was alright she just explained that she had never shared that the birth of her first child had cemented her belief in God, or even thought about it before. The second participant shared the impact of the loss of her son who had committed suicide, and how she had grown in her ability to be with others who were facing tragedy. After the tape was turned off she just wanted a few minutes break before going to a planned meeting. The third participant shared an experience at work that was particularly emotionally demanding. In talking this through, she seemed to consider for the first time how surprisingly well her first efforts at fulfilling a request to pray with this patient went. After the tape was turned off she implied she valued the time I had given to listen. I was struck by the weighty ethical implications of the nature of the interviews I was conducting. Prior to interviewing I had checked all participants had support should they need it but had not expected to ‘stir’ participants emotion quite so much by inviting them

to share their understanding of spirituality, and their practice experiences related to loss and spiritual care. Their personal and professional persona seemed very tightly knit. I felt at the time that listening to conversation in these interviews demanded a lot from me, and that perhaps I should not take on more than two in any one day, and I reiterated this on more than one occasion in my diary.

5.3b Participants' 'story'

My diary reflects a growing awareness of the pattern of each participant's account of their own spiritual development and how that impacts on their practice. There seemed to be a continuum of possibilities. Some arrived with a story to tell that reflected their own sense of a developed spirituality. Others began to voice an emerging story within the interview session, as if the opportunity to describe their understanding of spirituality in relation to loss exposed slithers of experience that suddenly shaped into a moment of spiritual insight and associated growth. A couple had no real story to tell, but their interview experience seemed to have 'woken them up' to questions they had never considered and therefore not addressed as yet. The following examples illustrate my thoughts.

The fourth participant interviewed as if she came to tell her story. An undiagnosed illness in her early adult years together with her evangelical religious views drove the focus of a rather lengthy personal account. Her 'lived experience' of spirituality and loss seemed very powerful in her personal life because, although she did share some practice experience in relation to these phenomena, there seemed a continual return to her story of illness, religion and family. In some ways, participant 2 had a story to tell of an enduring Christian faith, a career centred round family needs, and the loss of her son through suicide. This tapestry of personal experience had impacted her perspective on spirituality and directly accounted for her choosing to work with end of life care patients. Participant 5's 'story' is described in my diary as:

‘perceptive in understanding spirituality as timeless, spiritual awareness as heightened by situation, and philosophical in describing faith as understanding all things happen for a reason, that there is a point to our existence’.

Her story is one of search and an openness that is reflected in her responses that describe her approach to practice.

On the other hand participant 1 and 3 seemed to have a story that began to emerge within the interview session. In reflecting on the topics for discussion they seemed to open up an awareness of their life experience that they had not realised before. For example, participant 1 vocalised for the first time what must have been kept as a tacit awareness that when her first child was born she just knew there was a God. Participant 3 worked through the personal emotional challenges and achievements that she had with a particularly difficult patient, and in doing so, appeared to come to an understanding of her growth in a situation of sorrow.

Participant 11 and 12 were the youngest participants and each, in their own way, did not appear to have a story to tell ‘yet’. When interviewing participant 11 I think I reverted to being an educationalist facilitating participation rather than remaining purely in researcher mode as she was finding the interview difficult and said *‘I don’t think I’m going to be very useful’*. She was in no way distressed but seemed to be concerned that she would not be able to help. Facilitation ‘worked’ in getting started. Her comments reflected a nurse who practised holistic care and so implicitly addressed spiritual needs, but I do not think she had thought through spirituality as a concept integral to holistic philosophy herself. After interview she did say that the experience had *‘caused her to think’* and so, perhaps, had sown the ‘seed of a story’. Participant 12 had attended a hospice palliative care course in which spirituality had constituted part of the content. She had therefore thought through terminology and was able to give general comment on the topics for discussion. However, she had similar difficulty to participant 11 in exploring the application of these concepts in her practice. After the interview was finished she said that the questions were difficult because *‘you*

don't stop and think what you do and why you do it'. Once again such an insight might have seeded another 'story'.

5.4 Conclusion

Participating in research interviews proved to be cathartic for some nurses, in that they enabled emotional response, and catalytic for others, in enhancing self-discovery by provoking thought (Heron, 1989). The analytical focus of data has been the experiential features of spirituality as a resource for coping with loss. Hence, my interpretation of data reflects my understanding of each research participants 'life world' in relation to their experience in this context. This understanding has enriched my own fore-structure of the phenomena studied, and in this way, my understanding has transformed what I already knew. The stepped process of analysis undertaken indicates that the chosen research method has elicited data that contributes to the aim and objectives of the study. Details of the findings of this staged analysis are presented in Chapter 6.

Chapter 6

Findings

6.1 Introduction

This chapter provides details of the findings from semi-structured interviews with twelve nurses, five from hospice, four in community practice and three employed within a nursing home. Following data analysis five super-ordinate themes were found to recur in participant interviews. These were loss as a spectrum, belief as the pillar of spirituality, being a “spiritual carer”, becoming proficient in spiritual care, and belonging as the means of maintaining spiritual integrity. My understanding of the participants’ experience of spirituality as a resource in coping with loss in end of life care is evidenced by illustrative excerpts from interview transcripts which collectively comprise a substantive quota of raw data. In this way the trustworthiness of my interpretation of meaning of interview text is open to scrutiny.

6.2 Loss as a spectrum

‘Every time there’s a change or transition in life there are many losses involved’ (participant 8 Hospice p.12)

Research participants were encouraged to share their experience of spiritual care and loss in their practice contexts. It was evident from their descriptions that caring for people with chronic and terminal illness was an experience infused with issues of loss. Participant 8 went on to qualify this:

‘...but obviously there are spectrums of loss....’ (participant 8 Hospice p.13)

In this way he introduces the implication of significance in relation to loss. Participant responses reflect the importance of understanding loss from the patient’s perspective. A small incremental loss may trigger what seems a disproportionate emotional response in a patient if it signifies decline. As well as sharing details of personal significant loss in the throes of being interviewed nurses frequently indicated the emotional labour of repeated exposure to situations of significant loss in practice.

6.2a Dominant issues of loss

Another perspective on the spectrums of loss is illustrated in the descriptors used for dominant issues of loss. These differed across practice environments. It is not really surprising that hospice nurses, whose focus is on care of the terminally ill, associate loss within their working environment primarily in terms of the consequences of dying and death. This is described very factually by the most senior hospice nurse:

'...in the hospice environment it obviously is about death and dying because half of our patients that are admitted die, and all the ones - most of the ones - that are referred to us will die' (participant 6 Hospice p.7)

One respondent thought that the irrefutability of loss for patients and relatives commences with the diagnosis of terminal illness:

'I think the loss, the patient's and relatives' loss, starts at diagnosis... being diagnosed with a life threatening illness or being told that the disease...is terminal...' (participant 2 Hospice p.10)

Another specifies that the anticipated loss is that of a person and the roles and relationships they have had with others:

'I suppose immediately we think of someone dying'... 'And in terms of the family I suppose the most immediate thing you most quickly think about is them actually losing someone, dying' (participant 7 Hospice p.7)

Community nurses, who are 'guests' in their patients' homes, work with the family in situ and perhaps this is why they particularly convey their awareness of the impact of loss on the patient's significant others as circumstances change both relationships and the need for support. The losses were those of relationship and its associated activities, for example:

'...the loss of partnership, the companionship, the loss of making decisions, being alone...' (participant 9 Community p.10)

The multiplicity of losses that collectively represented 'life' or 'home' are seen as dominant issues for residents admitted to the nursing home. An awareness of the challenge for clients to integrate into 'life' in the nursing 'home' by one nurse is illustrated by the following:

'... I know if somebody says "you're going to a nursing home" I wouldn't want to come out of my room... most people aren't here by choice' (participant 3 Nursing Home p.12)

Similarly, a hospice research participant who had previously run a residential home reflected on the link between loss and the difficulty that some residents had had in integrating into life in a communal setting:

'And I did see in some cases, particularly those elderly people who were single, what a tremendous amount they had had to give up to come in, and what a huge adjustment they had to make to living in a communal setting, something that they'd never had to do since they were children. And that made a big impression on me, just how much they had had to adjust' (participant 2 Hospice p.5)

Locus of control is an aspect of personality theory that describes an individual's tendency to either believe that they are largely in control of their own lives or that some other agent, such as, God, environmental factors or other people determine their fate (Rotter, 1990). Some have pointed out that there is an assumption that individuals will become more prone to be external in their focus of control as they age (Aldwin and Gilman, 2004). However, residents who chose to remain in their room, the only space within communal living accommodation that they can call their 'own' is an example of one means by which they can retain control over their lives in a situation of loss rather than comply to invitations of professional carers. Regardless, the importance of encouraging them to emerge and engage in new relationships as a means of coping and avoiding isolation, a major theme in the cause of depression in older nursing home residents (Choi et al, 2008) is reflected in the following nurse's experience:

'We've had a few people here who, when they first come here, they don't want to come out of their rooms, they don't want people to see them like they are, they don't want... I suppose they must feel ashamed that they can't get up and walk, they can't do this, and so you try and work with people to try and stop... like... because when somebody gets isolated they become very introvert and very negative because they've... you know what I mean? And it's quite a common thing which can happen to quite a few people, so it's about trying to find them things that will get them out of their rooms' (participant 3 Nursing Home p. 11)

Another nursing home practitioner implies that the degree of loss faced by residents is so great that she is unable to imagine what that must be like. This inability to empathise with the situation is described sympathetically. She is however, able to recognise that the anger and frustration of residents is part of their response to loss:

'...I cannot put myself in the place of our clients coming in here because they are losing their freedom, their liberty, they're losing hopes, they've lost family, lost their mobility, lost their independence. I mean there's so much loss. It is very difficult because we deal with the angry, the frustrated, and I just believe that one should be tolerant...' (participant 4 Nursing Home p.16-17)

The comprehensive nature of loss suffered by those admitted to a nursing home is affirmed by another participant's response which suggests that residents have 'lost the lives they have had':

'...I mean people who are coming into a nursing home first of all they've lost their lives that they've had. You get some people who come here who have quite complex bereavements and... who've lost the people they care about' (participant 3 Nursing Home p.13)

Loss of their home, above all losses, was thought by another respondent to be more significant to residents than dying:

'... loss of family here, because a lot of the people here are here so long and they're so disabled they tend to lose a lot of visitors, some of them never have visitors, its quite hard to see that, but yes just losing their social thing, their work, if they have been in really quite high powered jobs they've lost that, they've lost their home. You know I think sometimes that's more of an issue than the fact that they're going to die...' (participant 5 Nursing Home p.14-15)

6.2b Consequences of loss for patients and their significant others

The participants' experiences of the consequences of loss for their patients generally appeared to be less specific to practice context. One respondent describes how significant loss is life changing not only for the person themselves but their significant others. The implication is that coping with loss is not dissimilar to managing the process of change:

'Well it's a change in your life, isn't it, so whether it's a chronic illness or an actual loss, it's a complete change to your life and the people around you, their lives as well, because you know generally speaking people have got friends or family who... and they work as a little network and if something happens to one of them it affects everybody' (participant 12 Community p.5)

Descriptions reflect the enduring physical, psychological, social and spiritual effects of loss that have to be coped with. Loss is often incremental in nature, particularly in those with advanced chronic disease, and is illustrated by the following description:

'I've a lady with MS (Multiple Sclerosis)...her mind is perfect, she can still work and does computer work and things like that but the fact that she can't empty her catheter bag for herself anymore, or...its those little bits of your life (that) are just slowly being taken away, its like a constant loss but over a long period of time... picking up a cup for example... she used to be able to do that 3 weeks ago, but can't do that today...' (participant 12 Community p.9-10)

One nurse's description of her experience of loss in practice affirms that deterioration is the driver for incremental loss

'... if their condition deteriorates further so that one day... someone has been able to feed themselves and the next day they can't,' (participant 5 Nursing Home p. 14)

Currer (2001) describes social death as an aspect of a relationship and of how one person perceives another. It is seen as the culmination of a sequence of events that results in an individual no longer actively participating in others' lives (Mulkay and Ernst, 1991). Participant descriptions indicating the consequences of loss for patients illustrate a variety of such sequences, for example, apart from observing the physical deterioration of patients, the following respondent describes how the dying patient becomes more introspective and socially isolated, even from those closest to them:

'...I think there is a very big change in the person physically, either extreme weight loss or extreme weight gain through being on steroids. People losing their hair, physical things, and also, I think when people are terminally ill they don't tend to be interested anymore in everyday things and they're obviously very much occupied by their impending death...so they don't want to talk about things that they perhaps used to

talk about with a partner or friend' (participant 1 Hospice p.12)'

The slow dissolution of personhood through terminal illness (Habgood, 1998) implied by the following description of how family members face the loss of the person they knew prior to biological death, is another example of the countenance of social death:

'...when somebody is terminally ill and they are obviously totally different people than they were before and everything is changed ...people say to you 'he is no longer my husband, 'she is no longer my wife, she is just...a completely different person' ...I suppose that is loss already before the actual death' (participant 1 Hospice p.11)

In situations where patients have dementia cognitive decline precedes physical decline. Friends and relatives therefore endure the loss of the relationship they had with the person for a potentially lengthy period before physical decline ultimately results in death. In this way social death is a situation relatives live with rather than encounter for the first time as biological death draws near. Sweeting and Gilhooly (1997) found that even when relatives believed the person to be socially dead few relatives treated them in this way.

'... (the) family of these people are suffering loss, particularly somebody who's got dementia, because the person they knew they're losing even though they are still there, it's not the same person, and learning to cope with that loss can be quite hard...' (participant 10 Community p.6)

Incremental physical changes together with social isolation exemplify the cumulative loss that occurs through the palliative phase of living with dying and the final decline that terminates in death. One respondent describes the process of dealing with these losses as a transition in which all those involved somehow undergo a preparation, a gradual coming to terms with and accepting the inevitability of losses associated with their own or their relative's situation. The nurse as professional carer contributes to this preparation, which is particularly important for those who will be 'left behind' following the death. This period of transition is about dealing with and hence coping with loss. Paradoxically, in this process, relationships are seen to undergo a transition in which those involved prepare for a loss which is

primarily the loss of a relationship. This paradox has been described by some theorists as anticipatory grief (e.g. Rando, 1997):

'I think there's an adjustment that goes on, certainly in the community, when you're caring for what starts as palliative care, if you like, we're coming to the palliative care stage and then we move onto the terminal care stage. And I think during that time, if you're looking at spouses or carers or family, children, in some ways there's a preparation that goes on for that loss, with the carers with those that are left behind. There's that preparation. When death is known, and you're involved with that as a professional, I think there is... you can see a transition going on and I know Kubler-Ross talks about this acceptance thing, but I think it doesn't come at the end of her grid, I think this comes very much when palliative care starts and I think the individual, if you like, is already coping with that loss, is already beginning to deal with that loss. So I don't think it happens at death at all, that's not the cut-off point, that's not the loss. The loss has already started, from a professional point of view I think that loss has already started and I think we're beginning to work on that adjustment within the family, the carer, daughters, whomever, I think the work it starts there because you know work starts with the carers, equally, as much as it does with the patient. So I think we're already working on adjustment to their loss. Because I think it happens doesn't it. It's not a cut-off point, you know, they've begun to lose that partnership, that companionship, that decision-making, that...that's happening, that's a gradual thing that's happening' (participant 9 Community p.10-11)

Deterioration results in patients needing more support. In this way their increasing dependence on others culminates in a sense of loss of control. One respondent describes the sense of frustration felt by patients who can no longer do what they could:

'...there's loss of independence, loss of the ability to function as they were previously functioning. I guess a lot of elderly people have talked about the frustration of loss, not being able to do what they could do and finding it very hard, even though mentally they're...they feel like a 20 year old but their body isn't and they hate that. So in that sense that's obviously a big loss, not being able to do things...you feel like you can, but obviously your body can't' (participant 11 Community p.7)

As the need for support increases the roles held by the patient are usually gradually relinquished (Lugton, 1999). However, where people have had an

internal locus of control and believe, as described above, that they are largely in control of their own lives evidence suggests that this tendency is likely to increase until middle age (Schultz and Schultz, 2005). Participant 7 describes a scenario in which a patient who had not only been in charge of his own life but had controlled those of his wives and families, strongly resisted relinquishing his controlling status to the point of becoming aggressive. The pathology of his condition meant that at times he was lucid and others not, the nurse describes how regardless, he agitated for control. This man's 'fight' to remain in charge may reflect his need to be himself, to live with dying as he has lived his life. Nurses can be uncomfortable with these situations. They tend to associate a 'good death' with being 'at peace' rather than struggle (McNamara et al, 1994). However, even Kubler-Ross (1970), who included 'acceptance' as the final stage of her theory of living with dying, did not specify that this would be done 'quietly':

'We've had a gentleman, again with a brain tumour and a fairly young family, who - I think he'd been quite a controlling person - and I think was still trying to run his family while he was here and wanted to leave on occasions. That was quite difficult I think because some of the time he was well aware of what was going on and other times he really wasn't, there was still this agitation with him all the time, he knew he had sort of lost his role in the family really and he couldn't be there with them, he couldn't be keeping his eye on what was going on and he couldn't organize them all, and that was quite difficult for his wife because occasionally he was quite aggressive with it as well. Which was quite difficult in a way I think for the children and his wife, really quite frightening obviously for them. And that...he had a wife, he had an ex-wife, and I think children with them and they were all coming in to visit... and he was still trying to run everything just as he liked...and it was difficult all round with all the family members and trying to help them, and trying to help him really, to understand that he wasn't well enough to just go and carry on as normal' (participant 7 Hospice p.11-12)

Anger as an emotional response to loss is described by participant 10. Helping individuals through what may be understood to be justifiable anger is seen to be most effective if the nurse remains calm (Sheldon, 1997). Information is used to facilitate coping by allowing preparation for inevitable loss and post

bereavement visiting as a means of promoting coping by assuaging any sense of abandonment, for example:

'We understand that, in certain situations people feel quite angry because they're helpless. Loss has occurred or is going to occur and there's nothing they can do about it, so they take their frustrations out in anger. But you get to know these people and afterwards they'll apologise if they've been angry towards you, but you just know it's a part of the process and you just have to help them through it really, and explain and remain calm. And I think with the terminal patient if you explain everything, what's going to happen, I think that helps them come to terms with the loss, preparing them for it. It doesn't make it easier, but I think it just makes it easier to cope, understanding helps to prepare people for it. Doesn't mean to say they're going to like it! -But I think with a little bit more understanding. And we try... if possible, we can't always do it, but if we have been looking after somebody palliatively and they die, we try and go back to see the relatives a few weeks afterwards to see how they are. Just so they know that we used to come in every day and see you but we are still around, we haven't just abandoned you because your loved one has died. I think that can be quite beneficial to people coping with loss' (participant 10 Community p.7-8)

Spiritual distress as a consequence of loss of religious faith by one patient seemed really harrowing. The research participant who described the experience was the most senior of the hospice nurses and she implied that she had never experienced nursing anyone as distressed before:

' I do remember a lady who was a really, really devout Catholic for the whole of her life and while she was poorly sort of took comfort from her religious beliefs and God, but when it got to about the last 5/6 days of her life I don't think I've probably ever seen anyone more distressed because she was questioning everything- you know, if I've behaved in this way, led a good life, acted in this way, you know I've led this good life, done everything right, never done anything wrong so why is this happening to me? And she was so distressed those last few days because she was questioning her belief, mainly in God, but in everything, you know, how she'd lived her life' (participant 6 Hospice p.2)

Roman Catholicism is a particularly strict form of Christian culture in which there is major emphasis on the sacraments and the symbolic significance of worship. This life is considered merely a beginning with death providing the conduit to 'fullness of life' (Green, 1993). The sacrament of extreme unction

performed by a priest for a dying Catholic symbolises forgiveness, healing and reconciliation. However, this patient seemed no less distressed after her priest's visits.

'...I mean I've seen people over the years who have been distressed and have been able to seek comfort, but I think she sticks in my mind because she died distressed, she was so distressed' (participant 6 Hospice p.3)

Evidence suggests that there are cultural differences in patterns of coping with loss even in societies that share fundamentally the same religious base (Wikan, 1988). Similarly, Walter (1999) outlines the differences that occur within a single culture of 'Englishness'. Participant 8 exemplifies cultural difference in comparing the rather melodramatic style of grief, which he observed when previously working in Ecuador with the spectrum of English cultural response to loss that he has experienced in practice at the hospice:

'Well I worked in South America in Ecuador, and out there when someone dies it's literally wailing, people collapsing on the floor fainting and incredibly melodramatic and everyone knows, the whole street will know about it and everyone comes and visits and they all cry and everyone's there, and it's just the end of the world, seriously big time! People throwing themselves in the grave and all that sort of stuff, it is pretty amazing. And so I've seen that. And having the wake, people have a wake and everyone from far a-field comes and has to pay their respects and that sort of stuff. So that's one extreme, and then the other extreme is where you see people in this country who... it's done and dusted, and they have to go on and get themselves busy sorting out what do we do now, this kind of no emotion shown and they have to get on with their lives and they have to get on with tasks of sorting out what's the next thing to be done. So there are extremes of reaction to loss. And that's not to say that either one or the other is right or wrong, it's just the way cultures and societies and personalities have formed that person to react in that way' (participant 8 Hospice p.14-15)

*'...here in this hospice I think we don't have that much of a cultural mix ...*** (name of health trust) is much more of a cultural mix...but even within English culture you've got a spectrum of response to it (loss)' (participant 8 Hospice p.15)*

6.2c Impact of loss on nurses

When speaking of loss from their own perspective nurses were referring to the death of a patient or person they knew.

Respondent 1 sought to understand the nature of loss she encountered in practice better. She implies a personal awareness of deeper issues surrounding loss related to dying that are rarely 'talked about' and appears to feel isolated in being 'the only one' in thinking this way. She found reading Kubler-Ross's accounts of talking to patients and relatives helpful as they seemed to affirm some of her own thoughts:

'... what I thought was (that it was) very good how sort of open, how very open she is with patients and their relatives about death and dying. What else can I say, there's just lots of things in there that I sort of immediately recognise and identify with. Which is also good because sometimes you don't always – or hardly ever in fact – hear, I would say, talk about things that go a bit deeper, and you sometimes wonder if... I don't know... you know how everybody else feels about it, and it doesn't matter of course also if you are the only one that feels about it in a certain way. But I just identified with so many things' (participant 1 hospice p.13)

A respondent from community practice describes, in general terms, how in getting to know their patients over a period of time, the relationship between nurse and patient that develops takes on a duality, one of a professional carer who is also a sort of 'friend'. Campbell (1984) describes this relationship as one of 'moderated love' that reflects '*consistent, skilled and informed concern*' (p.6). The death of a patient is therefore a situation of loss for the nurse as well as the family, but as the professional it is for the nurse to support relatives in their loss.

'Well loss...if you know somebody and they pass away then it does affect the people who are looking after them, it affects the family, and as a nurse we kind of have to support the family by doing bereavement visits and that sort of thing, you know, to help to deal with their loss and prepare them for a future possibly on their own, but to know that they've got the support of us as well. But obviously as a team it does...you, know, when you have looked after somebody for so long they've become almost...although they are a patient, they've become like a friend at the same time and if somebody dies it does affect you. It can be very upsetting and sort of difficult but at the same time we have to be professional and step in and help with the family...husbands, wives, children...to support them' (participant 12 Community p.4-5)

More specific reference to the challenge of loss for a nurse who befriends a patient was described by a respondent employed within the nursing home. She seemed to be comparing the length of time she had known the patients before they died with the length of time she had worked at the nursing home, hence implying the long duration of these relationships. Parkes (1996) describes *'grief as an expression of the attachments that people form with each other'* (pxiii). This is exemplified in the pain suffered as a cost of investment by this nurse in close relationships with patients who later died. This is very personal to the nurse as she uses 'I' when speaking of her loss. She explains, in referring to the death of her mother, how the impact of loss at work is compounded by the suffering of loss in one's personal life at the same time. Despite the investment of herself in care, again the nurse is very clear about professional boundaries. Although, initially comparing close relationships with patients to being like family, including speaking with some poignancy of memorabilia of patients in her home that she had been given as gifts over the years, she then goes on to affirm that she is aware of the difference. The problem of closeness and distance wherever care is professional is seen by Campbell (1984) as particularly difficult in nursing. Respondent 4 is perhaps affirming this difficulty when she describes how although she does not have close bonds with all patients, she looks after all patients professionally:

'...one that I lost a little while ago, he was here the whole time I've been here, and I've been here 11 years, and he 10 years. Daphne died this year and she was here 8 years...and...you're building relationships and each time they go that is a loss. And particularly if you've got loss going on in your own life, that's another thing. My mother died this year, it was difficult. We had a couple of ladies... died at the same time, and my mum was in South Africa and I can remember one day having this bizarre phone call with my sister in Johannesburg and the doctor hadn't turned in, (and the sister said) oh we'll wait and see what happens tomorrow, and I just lost it...so it is painful when they die. Yes, they're like family but they're not family. It's that... there is a divide, of course, and there are one or two that I've got bits of them around my home, you know, little trinkets that they've given me over the years...I've got African plates that Ossie bought me and, you know, Christmas they give you bits...you don't bond with all of them, you know, you do your best, you put your professional hat on and you look after all of them professionally but there are the odd one or two that really get

under your skin, and you think they could have been friends if we'd met in a different era or sphere or something'
(participant 4 Nursing Home p.27-28)

Similarly, the implication of nurses finding untimely death particularly hard if they connect with the patient in a personal way is exemplified by a community respondent. In this case the patient was also a nurse and in relating to the patient as 'one of us' the personal association with a member of the same profession may have made the death particularly upsetting for the respondent. Although she had looked after dying patients before, this was the first time she was the 'lead' nurse for a dying patient and in that sense, this situation was 'special'. Staff sickness in an already small team had further intensified this nurse's engagement with the patient during her terminal phase of care. The respondent was middle aged and her patient, who was an experienced practitioner (Sister in an Accident and Emergency Department) and so may well have been of a similar age. The bond that had developed between patient and nurse is evident in that, firstly, the patient took the trouble to write a card of appreciation to be given to the respondent after her death and, secondly, the degree of emotion that this card generated in the nurse when she read it. Davies and O'Berle's (1990) study found that preservation of the nurse's own integrity was central to her being able to care for patients living with dying at home. Sharing frustrations with colleagues was one means of achieving this. The intense sense of loss in this case may have been assuaged had the respondent had more support in both sharing the emotional burden of terminal care and some respite in the intensity of attending to this patient:

'...I'd spent such a long time with her and I found it quite hard when she died and quite upsetting. But I wasn't expecting the card (of thanks from the deceased patient) I think that came probably as a bit of a shock to me which probably added to my sense of loss with her. I don't know whether it was because she was a fellow nurse as well, 'one of us'. But perhaps because I'd just spent so much time with her in the few weeks leading up to her death' (participant 10 Community p.11)

The description of this particular situation also exemplifies how, apart from an initial release of emotion following the death of a patient, later events can trigger emotional upheaval. Privacy in coping with tears as a response to grief

is apparent in the nurse's relief that she didn't open the card in the house and break down in front of the patient's husband:

'...her husband left a message for us to go around and see him and I went round to see him and he gave me a card from her that she had written before she died, thanking me for her care. And for everything that we'd done, and I'm glad I didn't open it in the house, I took it away and opened it, I drove the car around the corner and sat and opened it and it just made me burst into tears, it was just too much, really. Because she was prepared for losing her life and she tried her utmost to prepare everybody else' (participant 10 Community p.9-10)

A number of other respondents gave examples of how once out of sight of patients and relatives their professional ethos gives way to the emotional expression of grief. They were quite choked with emotion as they gave their accounts of these incidents. Walter (1999) describes contemporary private grief among those of white English culture as that in which the pain of grief is expressed out of the public eye and that '*getting on with life*' (p.145) is the way in which individuals distract themselves from grief in public. He further explains that Stroebe and Schut's (1999) dual process model of coping with bereavement describes how individuals oscillate between expressing their grief in private and carrying on as normal in public. Participant 10's comment above and the following quotations from respondents, all of whom Walter would categorise as of white English culture, describe moments of private grief. One community nurse describes how she stopped her car so that she could weep:

'I had a great rapport with this family and was actually there when she died and I came away, again late, but I remember driving down the A20 and having to pull over and I just wept. Really wept and felt emotionally drained' (participant 9 Community p.17)

One of the nursing home respondents implies that others might think that she cannot cope if she is seen to cry, so she tends to find somewhere to cry alone:

'Sometimes I break down in tears...There's been a few residents who I've cried with. A couple of the staff who I've had a cry with. But most of the time I will shut myself away and have that cry... I think I do it so that people think I can

cope, I shut myself away...’ (participant 3 Nursing Home p.20-21)

Campbell (1984) compares the ‘moderated love’ of nursing care to companionship and describes how the closeness of contact with the patient means a costly mutuality for the nurse. This is illustrated by another respondent from the nursing home who was upset because she had not been present when a patient she had grown close to had died. She needed to arrange to see the deceased patient to say goodbye as part of her coming to terms with the situation:

‘We did have one lady die here who I was close to and I went and saw her in the hospital...at rest...I went and saw her because... I was so upset, I’d never said goodbye...I asked my manager at the time and she said I could arrange it just phone up and ask ...it did make a difference...I always thought I would never want to do that, I would never want to see someone that’s passed away, I’d rather remember them as they were, but actually she would just follow me all the time, you turned around and she was there, so it was such a loss that she suddenly wasn’t there’ (participant 5 Nursing Home p.19)

Bobinac et al (2010) differentiate between the concepts of caring for another person and caring about them. Caring for a person is present in people providing care and caring about them is present in the larger group of people who have a social relationship with the person who is ill, whether or not they provide care. Where ‘moderated love’ constitutes caring for another over a lengthy duration, ‘companionship’ may include the nurse in this larger group who have a social relationship with a patient. In this way a nurse could be described as caring for and caring about their patient. The emotional responses to loss of patients described above may therefore be attributed to their having cared about them as well as having cared for them.

The toll of coping with loss is described as more than psychological. Respondent 10’s description of emotional exhaustion implies physical depletion:

‘I think sometimes it can take quite a lot out of you without you realising and I just feel quite exhausted sometimes. And you think well I haven’t physically done that much today, but

you get home from work and you're so tired, you think well emotionally it's been quite a hard day' (participant 10 Community p.15)

6.2d Summary: loss as a spectrum

Dominant issues of loss differed across practice environments with hospice nurses predominately concerned with death, community nurses particularly aware of the impact of loss on the patient's significant others, and nursing home nurses aware of the multiplicity of losses faced by residents on admission as they relinquish their former 'life' and 'home'. Consequences of loss for patients generally appeared to be less specific to practice context. As well as physical deterioration driving incremental loss, the psychological challenges of loss included anger, loss of control, and the paradox of anticipatory grief for patients' significant others. Participants refer to the challenge of social death for relatives and the spiritual distress that follows loss of faith. Cultural patterns in coping with loss were also thought to differ. In getting to know their patients over a period of time the death of a patient was a situation of loss for the nurse as well as the family. Participants tended to grieve privately to facilitate their professional support for the bereaved.

6.3 Belief as the pillar of spirituality

'Faith is a belief that all things happen for a reason. There is a reason, there is a point to our existence' (participant 5 Nursing Home p.21)

In their responses some interviewees implied an understanding of the 'reason' for 'our existence' as a spiritual matter by indicating an association between spirituality and meaning and purpose in life,

6.3a Meaning and purpose

One response implied that spirituality involved matters of existential meaning:

'...just the meaning of life, what is the meaning and purpose of us being here other than to do the things that we do physically on a daily basis' (participant 5 Nursing Home p.1)

While another's associated spirituality with fulfilment achieved through enjoyment of life:

'...it's what makes up your individual world. Things that make you happy, things that interest you, things you get enjoyment out of life that gives you a fulfilled life' (participant 12 Community p.1)

This comment reflects a psycho-spiritual perception of meaning and purpose in life. Fredrickson (2001) suggests that positive emotions, such as happiness, broaden our thought-action repertoire and help us build psychological resource which can be drawn on at other times and in different emotional states. Our psychological resources impact our ability to fulfil our life's purpose. Even records of history and ancient philosophy, associate happiness with well-being and claimed that when we make full use of our cognitive capacities we are closest to our god-given function (Mohan, 2004; Scoffham and Barnes, 2011).

Respondent 8 conveys a sense of collective search, 'all being in it together', in that, in our life's journey of discovery we all partake in a search for meaning:

'Another way of looking at spirituality is that search for meaning isn't it? I think Frankl talks about the search for meaning, and I think we are all in that search...the journey of discovery' (participant 8 Hospice p.18)

In encouraging patients to find something that gives them a sense of worth in their lives respondent 3 is helping preserve feelings of purpose. Worth contributes to a sense of value and so this respondent's strategy is also one of generating and/or sustaining hope (Flemming, 1997):

'...from experience, different people have different things that they find important in their lives and its about encouraging them to do...or to find something that helps them to feel as though their lives are worthwhile' (participant 3 Nursing Home p.1)

Existential questioning fundamentally focuses on 'why' things have happened (Peberdy, 2000). Such questions can create considerable suffering (McLeod and Wright, 2008) as patients or relatives struggle to understand the meaning and purpose of what has or is happening to them. One respondent described a scenario in which a 50 year old patient was trying to make sense of the situation she found herself in asking the question, why? The patient, who was

described by the respondent as a ‘dolly bird’, had fallen from a balcony and broken her neck. As a result of this the patient was totally paralysed and angry wanting to know:

“why did they leave me like this?” (participant 4 Nursing Home p.19)

Such a question can be interpreted as either a question of causality or a question of meaning (Fredriksson, 1999). The nurse responded to the question as one of causality. Her ‘public’ response largely reflected the good intent of the emergency team in recovering the patient from unconsciousness:

‘...you’d sort of go back to basics and you’d say - when you were unconscious and you went into A&E and you (had) fallen off the balcony or downstairs or whatever it was, they tried to do good, because the rule is to do good not to do harm. And they tried to do good and the fact you’ve ended up like this wasn’t the intention and they didn’t know that when they brought you back to life’ (participant 4 Nursing Home p.19)

However, the question was evidently one that reflected the patient’s struggle to find meaning as her anger was not abated by the nurse’s response.

‘She went away nursing her rage and her anger and... she told me, if it didn’t work out in the community she was going to store up the tablets and overdose, and she would kill herself’ (participant 4 Nursing Home p.18-19)

The nurse however, had already indicated her ‘private’, judgement of the patient in stereotyping her as a ‘dolly bird’. She had heard that alcohol had been involved in the incident that had resulted in the patient’s fall. Without a diagnosis of disease due to pathological change participant 4 was judgemental in attributing the patient blame.

‘And the problem was her admitting that she was the cause of why she was in here. She hadn’t got MS, it wasn’t something that was outside of her control, it was something that she actively did to make herself here. And that, if she accepted that what I was saying was right, she had to admit that she was the cause...’ (participant 4 Nursing Home p.19)

When describing her inability to put herself in the patient’s situation in relation to the multiple losses associated with admission to a Nursing Home, respondent 4 seemed to be unable to empathise with patients but did convey

some ability to sympathise with them, (for example, see quote 6.2a: 79). She also understood that anger evidenced frustration and required her to be tolerant. However, in the scenario she describes above her private view of this situation shows little real sympathy or tolerance.

Questions of meaning are rarely answerable but understanding helps (McLeod and Wright, 2008). A more appropriate approach to existential questioning was reflected in participant 8's response to questions of untimely loss. He was self aware in acknowledging that he may come to certain answers himself about such questions but these may well not be right for someone else, and that any attempt to answer such a question for the patient or relative would merely be a platitude:

'...being there that's really all you can do, you can't say anything can you? The moment you say something it's a platitude and if you think you've got the answers you're in the wrong job basically. You know, you've got to admit there aren't any answers to certain things. And you may have certain answers for yourself but they may not be right for someone else...' (participant 8 Hospice p.16-17)

6.3b Religious and non-religious faith

In the throes of interview respondents returned to issues of faith in different guises. Their understanding of spirituality was one that incorporated religious belief alongside a range of understandings of what might constitute personal faith.

When asked to talk about what they understood by the term spirituality most respondents shared a little of their personal history or story. Many had been socialised into practicing a religion within their family culture and, in sharing these details they implied their association of the term spirituality, initially at least, as associated with religious belief. Although respondents were compliant to their family's religious practice as children, in adolescence and young adulthood most had questioned or strayed from their introduction to religious belief. However, a number had returned to their faith, albeit with a different perspective; it had been important for them to find religious belief in their own way. Culliford's (2011) consideration of a German study by Maria

Bindl in the sixties reflects that this pattern is not unusual. Findings from thousands of drawings on religious themes by Christian children whose ages ranged from three to eighteen years, indicated a developmental sequence in spiritual awareness in childhood that reflects a potential decline and then return to spiritual awareness. Initially 'God' or the 'Wholly Other' is experienced as simply an 'I-Thou' relationship (p.119). Then, as imagination and fantasy are reduced by the ability to reason their personal experience of 'God' begins to pale, the sequence continues with the neglect of 'God' by an increasing preoccupation with self. However, in their late teens some consciously return to the 'Wholly Other' in their endeavour to seek transcendence.

Respondent 1, for example, had felt positive about her intense Calvinist upbringing when she was a child. She was taught to believe that the Bible was the exact word of God. She read the Bible and prayed every day, prayer was said at every meal, she attended church twice on Sundays and went to Sunday school when young and religious groups for teenagers later. Her laughter when describing the duration of compliance in not questioning what she had been taught until she was about eighteen, seemed to suggest her surprise that it had taken her so long. Although questioning resulted in her 'turning her back', particularly on going to church, she describes the birth of her first child nearly a decade later as the moment of certainty in knowing God exists. She has searched but still not found the right church for regular attendance although she has regained a sense of feeling positive in knowing for herself the existence of God:

'...I grew up in Holland and was brought up in a strict Calvinist protestant environment. Which when I was a child, I thought of very positively...and I suppose I didn't really question too many things until I was, I don't know, 18 or 19...there was a time when I turned my back to a degree on religion, certainly as far as going to church is concerned...when I had my first child I was 28 so I think I had turned my back for about 8 years by then, I remember the moment he was born I thought God exists! I remember that. And then (I) think perhaps not going to church, but certainly for myself personally sort of changing and, what shall I say, feeling for myself the existence of God and sort of being more positive...I consider myself a Christian but its

certainly sort of very different from the way I was brought up' (participant 1 Hospice p.2-4)

Similarly, another respondent conveys the need to find for herself what she had already been taught:

'(Christian faith)...was kind of something I was brought up with but then moved away from and then chose it back for myself. So it's kind of been very much sort of part of my life but it's also something that having had it put there, I've then gone away and found it for myself' (participant 7 Hospice p.2)

This search for a personal interpretation of belief is evident even in those who have not strayed from religious practice in their youth and is illustrated in the following:

'I think that's changed over my lifetime, I think I used to...as a child I was brought up with quite a strong framework of religion, a Baptist background. My father was a minister of the religion. So I had a very sort of structured framework for my spirituality, and I guess my spirituality was attached to that faith and belief. But as I've grown older, gradually it has become more nebulous, really I guess. More...sort of...I think your religious framework is still quite important to your spirituality but spirituality is greater, it's bigger than the religious framework. And so I think I've described before when I was a child, that I had very deep roots. Those roots are still there, but the branches are slightly different, you know, the outward appearance is slightly different. So my sense of spirituality has changed enormously because of that.' (participant 8 Hospice p.1)

Respondent 4 had a contradictory introduction to religious faith. She was brought up in the Manse, which was the home of her grandfather, a Congregational Minister, because her father was away in the army. However, her father was an atheist and disapproved of her participation in church activities. Her personal conviction, or sense of a 'God', meant that she continued her personal search by trying out different styles of Christian religious practice. Her account clearly conveyed her sense of 'arrival' when she found a non-conformist church.

'I came from Wales...I had a grandfather who was...a Congregational Minister but I never knew him' (because he died when participant was 18 months old)... 'I grew up in the

manse as my father was in the army...And we were the children of the manse. And we had to perform on Sundays for visiting pastors, ministers. My father was an atheist...He really was anti-God... deep down I always knew there was something bigger than me'... 'I sort of dipped into what I called traditional religion, you know, Anglican church, singing in the choir, as a child - always with my father's disapproval. And then when ...I'd just qualified as a nurse, I went to see Billy Graham...I went forward and I've never looked back. And he's a personal saviour of mine and I live the life, a non-conformist church...' (participant 4 Nursing Home p. 3-4)

Outside of comment that was theistic in its reference to God or the religious and so implying allegiance to doctrine (McSherry, 2007) most interviewees did give further account of their understanding of the meaning of spirituality that conveyed a non-religious perspective. Connection with another person is not uncommon as a descriptor of an aspect of spirituality (e.g. Burkhardt, 1989; Twycross, 1999), but the ways in which that connection is described can vary. One respondent described connection with another person as a meeting of souls:

'So it's really making that connection with that person and acknowledging that person is a human being just like yourself, with an amazing amount of history behind them, just like you have, and that somehow your two souls have come together and there's a connection there. I guess that, in reality, is what I see as spirituality in... practice.' (participant 8 Hospice p.2)

The shared set of beliefs, values and behaviour patterns learnt within our culture influence how we understand our experience (Speck, 2001). It is not surprising therefore that culture is mentioned as influencing our understanding of spirituality. In addition spirituality is described as inherent within us. This is not dissimilar to McColl's (2000) understanding of spirituality as a human characteristic, our ability to experience and incorporate spirit into our lives. However, McColl (2000) believes that it is spirit that exists independently 'out there' and not 'lots of spirituality' as described by this respondent:

'...a belief, a part of oneself. From cultural, from upbringing, anything that's passed on...something that you kind of believe in yourself. Something, that's just personal to yourself; there's lots of spirituality out there but it's

*something that's inherent in yourself'. (participant 9
Community p.1)*

In describing spirituality respondent 5 implies that she associates this with being 'open' and without 'set agendas' in contrast to religions which are bound by dogma. She does not reject religions out-right but believes that they each may have something to offer and provide an eclectic understanding of faith. The shift from a collective view of religion to finding meaning for the 'self' is reflected in New Age philosophy. MacLaren (2004) describes this philosophy as having its roots in theosophy which is eclectic in that it includes Hindu, Buddhist and pagan theories. In this way the respondent's view of spirituality supports New Age philosophy:

'... I would say if I'm perfectly honest! I am quite open minded, I certainly don't follow a strict religious faith. I never have done from childhood and I can't see that I'll ever be inspired by one set of faith, I like different things from different faiths and don't like rules laid down by religion, its definitely the spiritual side rather than set agendas' (participant 5 Nursing Home p.1)

Being a person exists essentially in relationship and entails communication (Habgood, 1998). Traits of humanity, such as the ability to think, believe and have morals allow us to make choices (Williams, 2005). Hence, in choosing how we are with and how we treat others we contribute to our growth in 'becoming' who we are as a person. In this way participant 10's description of non-religious spirituality also infers spirituality is a constituent of personhood:

*'... I think it's about how you think and how you are and what you believe in. And I don't mean religious-wise, I mean morals...and how you treat people' (participant 10
Community p.1-2)*

There were very few specific examples of non-religious spirituality in participants' descriptions. Even the most comprehensive comment on this made by the participant who was explicit in not being religious herself, referred to places of worship. Although, the awe of inspiration of natural environments is also clearly inferred:

'You know, if I go to Canterbury cathedral I find that very inspirational and it is a very powerful place and has got some presence about it but, you know, again if I'm out in the countryside or, even when I was little in Devon, and

Dartmoor I find that quite spiritual especially like the prehistoric stone circles and the faith of people thousands and thousands of years ago inspires me probably more than faith of a lot of people today' (participant 5 Nursing Home p.1-2)

Respondent 1 owns that she is not clear when it comes to differentiating between religious and non-religious spiritual issues and describes the dividing line as 'blurred'.

'The thing is I think often the dividing line is blurred. So I'm not absolutely sure about some things, specifically sort of non-religious' (participant 1 Hospice p.7)

This nurse had an intense religious upbringing, and although had largely rejected 'church' in adulthood, maintained a strong religious Christian faith. Her particular culture of faith may value a more liberal approach to theological and spiritual issues but seemed to leave an understanding of non-religious spirituality outside her worldview. This was again evident when she later commented that there was a theoretical distinction between religious and non-religious spirituality but implied that in practice there may be little difference:

'...he (the Hospice Chaplain) is very good also for non-religious spiritual care. So perhaps there isn't that much... there is a theoretical distinction, but... anyway' (participant 1 Hospice p.10)

One respondent did make reference to activities that might be a source of spiritual fulfilment. The examples given were of physical engagement with nature. Digging the garden has a preparatory association with growth and snowboarding, a means of enjoying the very challenge presented by the elements:

'So for some that might be religion and God, for some it might be digging the garden, for some it might be snowboarding' (participant 6 Hospice p.1)

The religious beliefs of a number of respondents and the eclectic, non religious faith of participant 5 have been described above. The remaining respondents, if not practicing religion, described themselves as Christian, in still believing in God. The exception was participant 6 who made no mention

of faith or a personal stance on religion and, when asked, described her family as the source of the meaning and purpose in her life:

'Well I think for me, again, it would be my family – they're the thing that gives me meaning and purpose and encourage me when things are bad or I'm having a stressful time, yes that's what I would say.' (participant 6 Hospice p.6-7)

6.3c Faith as a resource to 'regulate distress'

Given then that most nurses participating were able to express a sense of faith, in the same way many had had this faith tested by experiences in either their current or past practice environments. Such challenges can result in needing to make sense of events, often by asking why? (Speck, 1992) In different ways the existential question 'why?' was raised by respondents who found it difficult to find the 'reason' for some things happening.

One respondent gave examples of both global dilemmas and the sudden, randomness of loss by a colleague at work as fuelling 'doubt':

'I think if you see really bad news, whether it's a world event like terrorism or something horrible its very hard to have any faith in anything you know. I do feel you just think it's so horrible you can't see any good or reason to why that should happen. Or people that are born and are starving and you think why is this? And is there an afterlife...even things at work, we had one of the girls here lost her husband yesterday, completely out of the blue...you just think why?...it's just sad...and I think at those times I do doubt things, I do to be honest. It is very hard to see a positive side or reason for that to happen' (participant 5 Nursing Home p. 2)

Similarly, several nurses reflected on past practice experiences in which they had been challenged by caring for young people who were dying. Societal expectation is one that associates dying and death with old age and chronic ill health. Hence, dying in youth within western society is considered untimely and often engenders a sense of struggle in those trying to make sense of such situations (Sheldon, 1997), for example:

'...I suppose it's easier to accept somebody who... either has a chronic illness or has a terminal illness if they're older, but if they're younger I think it doesn't seem fair. So I think that's where I sort of struggle a little bit' (participant 12 Community p.7)

Untimely death tends to create more anger (Sheldon, 1997) and this is evident in respondent 8's use of the term 'stolen' when referring to death of the young, hence implying an almost unlawful, illegitimate event. He is also reminded of his own mortality in reviewing his own age in relation to that of the young person dying:

'I think it's always difficult when there's young people who die. And when I worked in Ecuador I worked in a unit there with HIV and AIDS and in the early days, there weren't the anti-virals and young people were dying very young, you know. And that feels as if someone's been stolen away and that's really tough. And I find that tough with young people, if someone younger than me dies it really hits home, you know, it shouldn't be happening' (participant 8 Hospice p.16)

The resilience of her own youth is suggested by respondent 2 as the means by which she coped with the intensity of loss of young children in her early professional career. Bruce and Schultz (2001) describe resilience as involving skills that control anxiety and the perception of unremitting emotional pain. However, the respondent goes on to imply that she did not 'escape' the impact of these experiences in that they have left an enduring impression on her as she has grown in professional practice:

'Working with young children who have life threatening orthopaedic conditions and malignant tumours; babies with malignant tumours. At the time I think they distressed me but because I was young and resilient I took them in my stride, but looking back I realise how saddened and how...distressing they were. And then experiences like that have left an impression with me through my nursing career' (participant 2 Hospice p.2-3)

There were a number of examples of nurses comparing the dying patient's age with their own (participant 8 above for example), but only one who explicitly spoke of a raised awareness of personal mortality. This nurse who is in her twenties was referring to her experience while in her previous post, and therefore potentially a time when she was as young as a nurse who has achieved registration could be. She identifies the loss of a whole series of potential expectations that the family will have to face in losing one of its young members. Such losses are described by Bruce and Schultz (2001) as

non-finite in that the loss is continuous and reviewed over time; for example, parents may review their loss of having been grandparents when they are shown photographs of others' grandchildren. Her comment conveys the difficulty she envisages for the family coping with this loss of expectation and implies a tacit awareness of non-finite loss. In youth, her comparative age also raises awareness of her own existential angst in the following extract:

'...in my previous job...and dealing with young people and obviously that's always a tragedy, and it's very upsetting for us as professionals especially when somebody's young and it's all of a sudden and it hits the family and how are they going to cope, and their future, looking to a future without that person growing up and getting older or having family or whatever, you know, all those things that a person should be able to have if that's what they choose, it's just taken away. And you know dealing with that from an individual and a professional point of view is quite difficult because... you know I'm a nurse I have to support you but at the same time you're realising your own mortality as well...' (participant 12 Community p.6)

The transactional model of stress and coping describes stressful events as those appraised by the individual as a challenge (Lazarus and Folkman, 1984). In this way a situation that is particularly stressful for one individual is not for another. Some respondents found they were challenged in situations where the family circumstances of the person suffering an untimely death were close to their own family circumstances. One respondent, who was in middle age and who had children of her own found her self reflecting that it 'could happen to me':

'Sometimes you have people come in and die, who are younger than you, or they've got young children or it's just been a difficult situation, I think sometimes then you think oh that could happen to anybody, that could happen to me, how do I deal with it?' (participant 7 Hospice p.16)

Another example is a nurse, in late middle age with children of her own, who inferred that she was completely caught out by her emotional response to one situation. In trying to make sense of why this happened and why it stayed with her for so long she reflects on how she was almost putting herself in the patient's position and seemed to be worrying about how it 'would be' for her own family in those circumstances:

'I can only think of one time when I didn't cope... I remember that did stay with me a long time because I had never been that emotional, and I just wondered if it was because of the youth of the family, and thinking you know mine were around about the same age and how would it be...you know, it was almost putting me in the position of the patient that had gone, you know, that...the loss, the whole disruption of life through loss, and how would they ever cope and how did that child cope without her mum, and I was reasoning with myself, and I was thinking no she's got...older siblings...and her dad's great and she'll be fine and...not...worrying about her' (participant 9 Community p. 17-18)

One respondent, a graduate in theology, explained that faith can fulfill the search for life's meaning and provide a reason for living, a veritable 'rock to stand on'. However, things happen in the world that, 'rub' so 'hard' against that faith that it becomes refined over time to a point where faith is associated with embracing uncertainty. Although the nature of his work has caused him to question his beliefs, his faith has 'weathered' the buffeting of challenges he has faced in his work. However, his beliefs have changed, no longer compared to a stable rock but to a less tangible certainty of the uncertain:

'...I think it was Nietzsche who said that he who has a why to live for can cope with almost any how. So to have some reason to live for is very important, and your faith can bring that, and give you a certain rock to stand on...But then there's the flipside to that, if you have got a faith and things happen in the world that rub against that faith hard, it can really be very difficult to handle that. And I certainly found that in my work, it's opened up all sorts of questions about my faith, about my beliefs, and those as the years have gone on, have been refined tremendously. I think that's just part of growing up anyhow, to be honest. But working in patient care and working in an HIV unit, some of the things I've seen and some of the experiences I've had through all that have knocked me and knocked my faith and made me really have to reflect and rethink and come to new understandings and that's quite painful sometimes...I think it's just arriving at that point where you just have to embrace uncertainty really, you can't say anything is black or white' (participant 8 Hospice p.18-19)

Aranda (2008) supports the idea that coping in these situations is achieved by anything the nurse does to 'regulate the distress' (Folkman, 1997 p.1216). For some respondents their own beliefs or faith help them cope in this way. One

nurse, for example, made explicit reference to belief as a means of 'processing' situations of loss, a coming to terms with things happening for a reason:

'... my own beliefs as well, that's important, because obviously that helps me to sort of process it and think well, ok...it's happened for a reason...' (participant 12 Community p.11-12)

One respondent spoke of her belief, in relation to faith as the means of helping her accept what we do not know:

'...I don't call myself religious but I am a Christian...there's an awful lot we don't know, we're not supposed to know, that we just have to believe in. And I have that belief' (participant 2 Hospice p.9-10)

Another's view was not only accepting that 'things...happen' but believing they are pre-destined as part of a 'big plan':

'...but I believe there's a big plan for everybody and everybody's part is probably charted to a certain extent and you have to accept some things are going to happen' (participant 10 Community p.16)

Compassion is described by Bierhoff (2005) as a concern for the suffering of others that makes you want to help them. One respondent's comment inferred the link between faith and compassion when dealing with challenging situations. Faith supports compassion by generating a personal resource in the nurse, in that compassionate understanding promotes tolerance of difficulty in others:

'I think my faith teaches me you have got to forgive and be understanding towards them especially if somebody's is going through a difficult time. They might not behave in the way they normally behave, so you just need to be understanding' (participant 10 Community p.17)

6.3d Personal philosophy as a coping strategy

Regardless of faith many nurses seem to have developed a personal philosophy that helps them cope with repeated exposure to situations of loss. There was some suggestion that coping philosophies were linked to particular personal qualities necessary to survive in end of life care environments. However, one nurse felt that when she qualified, more than twenty years ago,

nurses were the 'stoical nurse type'. Individuals drawn to nursing as a profession had a tendency for particular traits that supported stoicism, and were strengthened further in being a nurse. The challenges of nursing are seen to demand that you 'keep going' and do not get 'upset all of the time'. The primary focus is outwards, towards others, family and patients who need support. Historically there were no formal means of support and getting upset may have been considered 'a bit of a weakness':

'And part of it, I think, is that sort of stoical nurse type thing – I think you have those traits that's why you choose nursing as a profession and then it reinforces them. Especially I think if you qualified when I did, more than twenty years ago. That was reinforced. But nowadays it's much more acceptable if a nurse gets upset or finds things difficult, but sort of twenty years ago you just had to get on with it because you didn't have supervision and it was probably seen as being a bit weak if you got upset, and you just kept going. So I think you have those tendencies, which is what makes you become a nurse. And then the nursing profession, which makes things hard for itself, reinforces them...but it's a case of you know you're dealing with horrible things and death and dying at times, so it's no good getting upset all the time, and there are times when you do, but generally you're there to support the families and the patients so you have to keep going even at times when you feel you really don't want to' (participant 6 Hospice p.13-14)

In a study by Eley et al (2010), exploring temperament and character traits in nurses and nursing students, outcomes were congruent with a profession requiring persistence, self directedness, cooperativeness and dedication and warmth. Hence, participant 6's comment, that infers that nurses are not as stoical as they once were, and so perhaps not hide their feelings in the face of emotional challenge as much, may be more a matter of a shift in the wider culture of 'Englishness' than in nursing culture itself.

A ploy used by research participant 6 to cope in a situation of loss is by comparison of loss; the nurses' loss paling into insignificance in relation to the loss suffered by the patient and relatives:

'Yes, you're there (to support families and patients)... yes. Because however bad it is for you, it's not as bad as it is for them' (participant 6 Hospice p.14)

Another nurse, who was middle aged and fulfilled the criteria outlined above for a 'stoical type' nurse in relation to the era of her training, inferred that for her coping was more a matter of life skills that had come with experience. Eley et al (2010) found that those of middle-age, regardless of whether they were nurses or nursing students, scored highest in persistence as a trait of temperament, and tended to be more reliable and tolerant in character than those of younger age groups. Then, given that the nursing students will have had less professional experience, it may be that the experience respondent 9 refers to below is as much to do with life experience as that of nursing:

'Because often I will think how do I go on to the next visit having been there at a death or dealt with bereavement or, you know, loss if you like...and I think that only comes with life skills, to be honest, I don't think its anything you can teach people' (participant 9 Community p.16-17)

One nurse coped with challenging emotional situations by bearing in mind that it was 'the other', the person who was actually suffering, who 'owned' the loss. Focusing on the positive outcomes of support offered to patients helped her cope in situations of loss:

'A lot of the time, if you can do something to help, or if you can't change the situation you can do something to help them through it or, you know, you can facilitate something that they want doing. That gets you through it because you've done what you can, done something positive and it worked out well. Sometimes situations are very, very sad and there's no getting away from it no getting around it, nothing you can do about it, you come out of a room and you cry and then you talk...we talk amongst ourselves, and then you get on with it. Because it is a very sad sometimes, you kind of bear in mind it's not your personal loss. It's... just being there for someone else and I think you know if nothing ever got to you, you probably wouldn't be human. But it's not the same as being that person who is actually suffering that loss, you know it's upsetting at the time, but you go away and you can talk through it or go away and do something else, and it's their life not yours so...its how you deal with it when its all the time' (participant 7 Hospice p.14-15)

Similarly, another respondent focused on the sense of achievement of doing what the patient wanted. 'Doing it right' was what was important.

'But I ...strangely when everything goes right, even though they have died, you actually feel a sense of achievement that

you've done it right , you've done what they wanted...'
(participant 10 Community p.12)

6.3e Summary: belief as the pillar of spirituality

Faith is a spiritual resource in life's search for meaning and purpose. Questions of meaning are rarely answerable, but understanding the need for such questions helps. Participants implied their association of religion with spirituality but also included non- religious perspectives of spirituality in their accounts, such as, connection with another person, being 'open' without set agendas, and that spirituality is impacted by culture. The difference between religious and non- religious spirituality was described by one nurse as 'blurred'. Situations of untimely death were particularly testing for participants. When the family situation of the patient was close to their own nurses found it difficult to make sense of their own feelings and emotions. However, personal belief and philosophy provided a means of accepting or processing loss, whether reliant on being stoical, or focusing on getting care delivery 'right'.

6.4 Being a "spiritual carer"

'...tasks have got to be done and they feel as if they're getting in the way, but actually it's the way you do those that brings in the spirituality' (participant 8 Hospice p.12)

The very substance of Heideggerian phenomenology is concerned with differentiating between 'Being' and the human being (Crotty, 1996). Understanding 'Being' influences how we behave towards other human beings. In the same way as choosing how we are with and how we treat others contributes to our own growth in 'becoming' who we are as a person (e.g. participant 8, 6.3b: 97) we can contribute to the personhood of other human beings we encounter. The term nurses use for human beings who access healthcare is often 'patient'. Holistic end of life care requires nurses to encounter their patients as persons in not only considering their physical care, but their psychosocial and spiritual care as well (Department of Health, 2006; Department of Health 2008). However, participant 8 points out how easily nurses can lose sight of holistic care of persons by perceiving patient care in parts:

'I suppose we're quite dualistic about spirituality and think there's a physical and spiritual or the sacred and the secular, but actually there isn't that divide' (participant 8 Hospice p.12)

In their responses interviewees reflected an understanding of the significance of particular ways of behaving towards others to develop trust and rapport and the importance of personal replenishment to maintain spiritual well being in the face of recurrent loss.

6.4a Rapport and relationship as a spiritual resource

To care for another is to value them. In order to provide care it is important to know something of the situation and needs of those requiring care. In giving accounts of their experience interviewees provided examples of ways in which they have used themselves to communicate with patients as a means of identifying their needs. These examples reflect the importance of establishing a rapport as fundamental to a relationship of trust. Trust opens communication by the vulnerable of significant matters, which if shared can facilitate coping, for example:

'I myself like to think, and I'm sure other people do that as well, that if you have built up a rapport with people that they might well, you know, sort of talk to you, and sometimes even just talking about it or expressing fears and anxieties is sort of partly helping, if not completely, but yes...just sharing the burden, but I think that happens when people feel they have a rapport with you' (participant 1 Hospice p.15)

Communication that reflects spiritual caring is described by Morse et al (1992) as a style that to some extent predates professional learning. Reflexive responses are patient-focused and triggered by the emotional insight of the carer. The emotional involvement reflects the carer is 'connected' and able to identify with the sufferer. In this way, immersion in another's reality results in sharing the experience or 'burden' of suffering. Such care is described by James (1989) as emotional labour and demands both strength and energy. It is therefore not surprising that this respondent speaks of her need for 'replenishment' after an emotionally demanding day (6.4b: 117)

Caring conversation is a means of exploring the patient's personal suffering (Fredriksson, 1998). Several participants considered conversation the most natural means of establishing a rapport and conducting an assessment of spiritual need. Metaphor was used by respondent 8 to convey his intuitive unease in using illustrative questions set out in a more formal assessment document rather than conversation, in that, it did not 'ring right':

'And I suppose you've got to start somewhere. But I find that when you're in with someone, to start asking those sort of questions as a spiritual assessment just doesn't ring right with me. I think you assess someone's spirituality by being with them for a period of time, and it's from the conversations that flow from that. But you, I think if you've got a sheet which is a 'spiritual assessment' and you have got to fill it in during admission and you feel as if you've got to ask these questions, it feels very forced and very artificial. Whereas if you've had 2 or 3 shifts with this person and look after them and had conversations, from that you can elicit a lot more information which sort of defines where they are coming from spiritually' (participant 8 Hospice p.7)

Others also prefer conversation to questioning as an effective means of understanding how others feel, their beliefs and what it is they need. Respondent 10, for example:

'I don't think you should underestimate talking to a patient about how they feel, their beliefs, what they want because you find out far more by doing that than just by asking them a few questions. If I need to go and find out about a patient I try not to go in and just ask them questions, you might have to start off initially with asking a couple of questions, but you then let them talk and you learn far more about them that way than just asking questions' (participant 10 Community p.4-5)

Respondent 11 inferred that in her previous posts the focus on assessing patients' beliefs differed depending on the care context. Elderly patients admitted to hospital for palliative care underwent a more focused interest in their beliefs than did patients admitted to hospital for cardio-thoracic surgery:

'So yes there was a lot more input from ... in terms of finding out what their religious beliefs were in that area than there would be in the cardio-thoracic' (participant 11 Community p.3)

In her current practice as a community nurse she does not question but describes an holistic approach to her assessment of need, explaining that:

'...there's more to nursing than just literally going in and doing a task, there's emotional support, there's... you know.... understanding their feelings and letting the person talk about things...being concerned about the person as a whole' (participant 11 Community p.6)

In 'being concerned' in this way she is made aware, or 'hears' of need:

'...from patients themselves volunteering that information' (participant 11 Community p.4)

In their classification of need Ewles and Simnett (2003) describe a felt need as one that an individual has identified, where there is some difference from their norm. In being supportive, trying to understand how her patient feels and letting them talk participant 11 is facilitating her patient to seek help in overcoming this variation from the norm by their volunteering the information which will make it an expressed need.

However, respondent 9 felt a written document including guiding questions was useful in initiating a spiritual assessment. Ritualistic practices are described by McLeod and Wright (2008) as those prescribed for all accessing a service. They acknowledge the importance of an appropriate attitude by the nurse performing the ritual but argue that performed thoughtfully they can 'open space' (p.136) for reading spiritual need and in the process promote healing. Although respondent 9 indicates, quite firmly, in her use of metaphor the importance of accepting the patient's response if the 'barrier is up' and they do not wish to discuss this aspect of care further, she again uses metaphor in indicating the need for assessment to be ongoing, and not 'parked' because the patient's needs change:

'...sometimes it's hard to do this assessment without the documentation so I think if you hit the documentation and you get to an area of spirituality, cultural beliefs etc, I think you just ask the question, what's on the document, and I think you know, following on your questioning, would be whatever the patient replies. 'I don't believe in anything', 'I have no spiritual belief,' you know, no... they don't want to go there. So that's quite difficult. But you've got to abide by that, that's their wishes, they don't wish to discuss anything and they

don't want to go down that line. So that's it, the barrier's up if you like...I think it changes, as you're nursing people I think the assessment's not all parked, it changes... it's a progress, it changes and maybe you'll get to a point in the last few days where the patient will ask, where they will just throw up a question where you might think well maybe they do need a priest or a vicar or some kind of something to latch onto' (participant 9 Community p.4-5)

'Latch on to' is again use of metaphor, and conveys the patient's need for support.

Considering patients or residents as 'whole' persons is a central tenant of 'holism' in nursing (McSherry, 2007). The nursing home environment in which respondent 4 is employed manages care by identifying a particular 'named' nurse for each resident/patient:

'... I don't just look at the person on the bed I look at the whole of them. And those that I'm responsible for, in other words the ones that I'm named nurse for, I go out of my way to get to know the family and to find out what's best for them' (participant 4 Nursing Home p.3)

Having a named nurse facilitates familiarity for patients, in that they know who is particularly responsible for their care. It also provides a conduit for the establishment of a rapport by the nurse so they are able to particularly focus on the needs of specific persons and get to know their relatives and significant others who visit and so constitute a continuity of the patients' social network. However, patients need to be the primary source for establishing what's best for them; for this to be otherwise, as inferred by participant 4 who goes out of her way to get to know the family who can then let her know what's best for the patient, may be matriarchal and undermine the patient's autonomy.

Familiarity was also thought to facilitate a relationship that allows patients to be comfortable about sharing how they feel when visited by a nurse in their home:

'...well, after they get to know you, but even sometimes, for them to be able to talk to you to express how they're feeling, worries, anxieties, to allow them to do that and I guess to make them comfortable that they can do that...' (participant 11 Community p.6)

Again confidence and familiarity are linked by participant 10 to patients being comfortable and being willing to talk. However, she goes on to imply that sometimes she intuitively is aware of a need in people without being able to give an account of why this is other than *'you just sense things'*:

'...through talking to people and being quite open with them, letting them lead the way when you're talking to them about things. Gaining their confidence really, because then they're more comfortable around you and they'll talk about things and then once you get to know somebody you can recognize things in them easier than you can a stranger. But then sometimes you can just pick things up, you just sense things, a need in people, without understanding why you sense things you just do' (participant 10 Community p.3)

Similarly, a Hospice respondent used the phrases *'you sort of sense'* and *'intuitively recognise'* in relation to being aware of spiritual need:

'I think sort of talking to people or being with them, you can sort of sense spiritual things and often... or people might say things to you and obviously not usually sort of direct... sometimes people tell you directly about a spiritual need, but not always. Where I then sort of – I don't know – intuitively recognise spiritual needs' (participant 1 Hospice p.5)

She went on to describe a patient scenario to illustrate when she had found intuitive 'sensing' occurred but could not find words to further explain the experience of 'sensing' another's spiritual need:

'I don't know if I can really explain to you. I remember a young person being here, in her early 30s, who was terminally ill and she was just, though I suppose you could just imagine anybody in a state like that, it's obviously sad and depressing because nobody wants to be terminally ill and in their early 30s. But we used to talk, obviously talking about nursing care things and sort of needs, so let's call it physical needs that had to be met, or nursing care needs. But there was always... I could always sense that there were far greater things on this person's mind, and I don't know if I can describe it any better than that, just this sensing' (participant 1 Hospice p.5-6)

Verbal communication is not always considered necessary in establishing a rapport, but the supportive presence of just sitting with a patient may induce sufficient confidence to enable them to begin to share their worst fears.

Pettigrew (1990) suggests that the healing power of vulnerability comes from the nurse's willingness to stay with the patient rather than try to say or do 'the right thing' (p.505):

'...sometimes patients just don't want to talk about things or perhaps find it too difficult...and sometimes just sitting with them. And then I have experienced myself that... sometimes you don't need to say anything and sometimes you can just sit with a patient and nothing has to be said or will be said, but...sometimes, you gain somebody's confidence and then they might sort of talk about things, or just express their despair or just express that they just don't know what to do' (participant 1 Hospice p. 14)

Analogy in comparing life to a 'journey' and metaphor in describing the way in which 'the world unfolds in front of us' are used by respondent 8 to set up a sense of experiences shared by patient and nurse and in so doing the contextual basis on which the presence of the nurse in actively listening to patients is also considered to be comforting. The process of active listening is one of consciously paying attention, searching for meaning and understanding and so interpreting what is being said (Kemper, 1992). Active listening not only facilitates identifying spiritual need but is also seen as a way of giving spiritual care:

'I think it's the whole of comforting, you know we're all on a journey and we're all sort of on a journey of discovery I suppose, as the world unfolds in front of us, and in some ways, every day is a brand new day and brand new things happen and it's true for our patients and some of those things, those new things that happen, can be incredibly overwhelming particularly when people are coming to the end of life. And somehow just to be there alongside them and being on that journey of discovery with them I think is a way of giving spiritual care. So just being able to listen, listen beyond words, listen to what's really coming from somewhere deeper and trying to learn that intuitive ability of actually not just hearing someone's words...but actually there is maybe something much deeper behind those words...and not necessarily coming to conclusions about that but just being aware of that...and listening in case that person wants to talk through that' (participant 8 Hospice p.10)

The same respondent proposes that the ability to connect with something deeper in people can be learned, and that once 'felt', the power of this

investment in another becomes almost addictive and potentially perpetuates an ability to focus on spirituality:

'I think you can learn to do it. I think some people are naturally more able to do that, just partly their personality or their life experiences that brought them to that point. But I think once you've done it once or twice, once you've actually tried to connect with something deeper in people once or twice, and you see how powerful that is, you get hooked in! And you keep on doing it and it keeps on happening and it reinforces continuously that whole spirituality thing really' (participant 8 Hospice p.11)

However, apart from personality and life experience, an individual's aptitude to learn this skill is seen to be dependent on their approach to patient care. Fredriksson (1999) describes two modes of relating to caring conversation. One mode is that of contact in which nurses 'hear' what the patient needs, completes the necessary task and so their presence, in 'being there' for patients, is one of problem solving. This mode appears to equate with the 'very efficient' nurse, described below by participant 8, who may have difficulty in connecting with something deeper in others. Fredricksson's (1999)' second mode is one of connection in which nurses 'listen', and so not only remain silent themselves but also silence their mind so that it is not distracted by other thoughts but focus on 'being with' the patient they are caring for at that moment. Hence, nurses who participant 8 describes as focusing primarily on the person they are dealing with and address the tasks of care within that context are more likely to have an aptitude for connection:

'It also depends where people have come from, where they've worked, their working background, so you've got some staff who are very efficient and need to get the tasks done, and the task is the focus, and then you've got other staff that actually the task is secondary and the core of a person is much more important, and trying to connect with that. And of course you can't forget the tasks, and that's the difficult thing isn't it, it's trying to find that balance really. Because it's very easy to just suddenly forget about the tasks completely, which is very impractical, I mean spirituality is earthy at the end of the day so actually giving someone a wash is spiritual' (participant 8 Hospice p.11-12)

One of the youngest participants not only emphasised the value of listening to patients, but also evidenced her awareness of the implications of age

difference on understanding feelings. However, this does not detract from her using the present moment of nurse- patient interface to encourage coping by sharing her positive observations of aspects of the patient's current situation:

'To be able to listen to someone, and obviously for me I'm very young and you don't want to patronize them if they're very old, that's...you know, I don't think that's appropriate, what do I know? I'm not that age, I couldn't possibly understand what they're feeling, but I can listen. I can...may be point out things that are happening in their life that is good, that are going well, or family that is supportive, or things that they are doing, to maybe show that there are some things that are good in life' (participant 11 Community p.9)

Time as a commodity was inferred, or referred to, by many respondents in their accounts of communicating and being with patients. It was important that patient's had 'got' time to talk to the nurse and for the nurse, such time provided the means of building relationships with patients:

'To be with people so they've got time to actually tell you what their need is or even just to sit with them so they can talk generally so you've got more to build on the basic relationship' (participant 5 Nursing Home p. 4-5)

One of the oldest respondents experience reflected the need for patience in 'giving' time to those in her care. Patient and relative stories that were reiterated over and over again were seen as being potentially beneficial for them and therefore the nurse felt it her duty to give the time to listen to their story each time it was recounted:

'...they have experienced a tremendous amount along the way to the point where we see them when they come in. I think it is really important, that we...remember that and give and enable the patient and relatives to retrace their steps sometimes and we see it often, some families don't want to go there, but others have to go there time and time again, they have to retrace their steps and they have to verbalise their journey over and over again. And sometimes it's hard, you think oh I've heard all this before, but I think you need to stop and think no, I've got to give them this time to get there because I feel they're beginning their healing process by doing that if that's what they need to do' (participant 2 Hospice p.11)

Another very experienced nurse appeared responsive in ‘finding’ time for unplanned, but significant conversation that ‘always’ commenced at the moment of leaving a patient’s home. The skill is described as not trying to answer the unanswerable but in letting the ‘other’, whether they are patient or relative, just bounce their concerns off you:

‘...and there’s always the door, as you’re going out of the door, the question - always happen don’t they – you know, the husband will say how long is it going to be, or what’s it going to be like? And then you get into the whole conversation bit, you know, you can be stood on the doorstep for half an hour. And it’s realizing that ‘gosh, that’s where the work’s done’... I think the real skills have come in dealing with those questions that can’t be answered, but just giving time really, just letting them just bounce off you I suppose.’ (participant 9 Community p.18)

Being sensitive to communication needs in this way is both compassionate and authentic (Golberg, 1998). The physical presence of nurses as professional carers ‘being there’ for patients and relatives is moved on to their ‘being with’ them psychologically (Speck et al 2004).

Sometimes, despite attempts to develop a trusting relationship, patients were unable or unwilling to share what was troubling them:

‘We had somebody once who... the problem was she didn’t... you couldn’t get to the bottom of her pain and sometimes she would start to talk about other things that were obviously on her mind, but if you tried to follow that through suddenly she would be in terrible pain and you would have to go and get something for the pain and you’d think actually a lot of the pain is spiritual pain and she started to deal with it and then couldn’t, couldn’t deal with it. It seemed very much (that) way anyway....She was in so much pain in the end but still no... and should have been totally sedated really, it seemed like she was but she was very well aware of things still and I remember going to talk to her and just gently touched her hand and then said something to her and you’d have thought she barely wasn’t conscious and she said ‘oh that’s... whoever you are, I know the arms, I know who you are’ so she was very well aware still of what was going on. And still very agitated, but she just wouldn’t open up about it. I mean we had half an idea about some things but it never all came out. She just wouldn’t deal with it’ (participant 7 Hospice p.3-4)

Respondent 12's description and reflection on relevant past experience that she brings to her current community practice raises a similar dilemma. If talking through situations is a primary source of support in helping patients and relatives cope by 'processing' or making sense of their situation how do professionals support those who do not want to know the details?

'You know, you can only be there to try and support them and talk them through things that have happened, why they've happened, how they've happened, what then happened... you know what I mean, you know, if an event happened, explaining to them well this happened for these reasons and because of these reasons it's like a spiral... just trying to let them be able to process the actual situation. Because it's so tragic that sometimes you just need... I think the facts help... But then you do get people who don't want to know anything and then that's very difficult because... especially if, say, for example, somebody's diagnosed with cancer – they don't want to know... how do you support somebody who doesn't want to know what you know about them, how can you support them as a whole person through their journey if they can't accept it themselves?' (participant 12 Community p.7-8)

The answer to the question, at least in part, appears in her own description in 'being there' and in her action in respecting their decision not to talk about it until they are ready do so

6.4b Replenishment

Nurses need to maintain their own well being, their personal spiritual integrity, if they are to provide spiritual care in situations of loss. Therefore the nurse's commitment to companionship in her professional caring role needs to be off-set by a life outside the work environment that has its own richness so that relationships with patients remain balanced (Campbell, 1984). A number of respondents describe ways in which they get back to 'being themselves' outside of the work environment. The first interviewee found it quite difficult to find the right words to describe the need for some sort of recovery from a 'bad' day at work or a feeling that is not quite feeling 'down'. She eventually described needing replenishment, a term that could apply to other participant's experience:

'If I've had a bad day at work, Locatelli's violin concertos cheer me up no end. No its not cheering me up, its sort of...I

wouldn't say I go home feeling down because that's not the right expression, but sort of listening to that music it just does something for me...Looking at art, it certainly absolutely lifts my spirit, a very big thing. That has always been the case, although I've never really thought about it much...and to a slightly lesser degree being at home and doing something I like to do. So if I had no time for that then I would feel that I would not be sort of replenished' (participant 1 Hospice p.16)

The means of getting back to being themselves seemed to be associated with solitary activities. Participant 8 makes regular, formal arrangements to be alone in order to find space to reconnect with himself:

'I'll go away for a weekend in retreat...where I am just on my own and just find the space to be myself and not to have to think about anything particularly but just to go for long walks or just be in my own company and I might sit in silence, look at the view, just try and reconnect with myself, get in touch with myself again a little bit. Because quite often when you're just dealing with people, tasks and things you feel as if you're part of a process, you aren't actually really feeling in touch with yourself, not feeling grounded in yourself. And I find that (at retreat) I can bring myself back into myself...' (participant 8 Hospice p.20)

Similarly, participant 12 chooses to spend time out without human company to lift her mood, perhaps providing a break from any expectation to communicate:

'I garden! I have a greenhouse so I potter around in there for a while, and I walk the dogs, so they're my two things really' (participant 12 Community p.12)

Apart from replenishment another key issue inferred by several participants is the balance that home life offers:

'...I do believe home has got to be...your outside of work life has got to be in good balance for you to be able to work here effectively.' (participant 2 Hospice p. 19-20)

Family responsibilities appeared to be an effective distraction from work. The contrast in environment and activities shifted perspective, for example:

'For me personally though it's also having a family so you're not doing that all day every day, you go home and do something completely different' (participant 6 Hospice p.4)

One respondent implied that the journey home allowed for the transition from the role of the nurse to a return to being a mum again:

'I tend to find, to be honest, that by the time I get home, you walk in the door and you become a mum again, you haven't time actually to be thinking about work too much and dealing with all the problems that are thrown at you the minute you walk in the door. I think it is important as well to have a life outside, to have things that you're busy with otherwise. Because otherwise it probably would be easy to take it (work) home' (participant 7 Hospice p.16)

Another respondent seemed to have a more complex home life with her family commitments often being 'elsewhere' and so outside the home after work:

'But I think on a daily basis you do have to get on, you know, I've got a family at home and, nine times out of ten, I've commitments elsewhere so I have to meet those commitments regardless of what's happened at work' (participant 5 Nursing Home p.18)

In the same way that participants have identified that listening to patients and giving them time to talk through their concerns is important so too many of these participants turn to their wife, husband, boyfriend or parents at home for a listening ear to talk through their concerns. Some identified what their chosen confidant had to offer, for example participant 8 valued his wife's understanding, but also her being a nurse was mentioned and therefore probably significant:

'I mean I talk to my wife...she's a nurse...she's very understanding so I can talk to her about anything, anything goes' (participant 8 Hospice p.19)

Participant 12 was explicit in valuing her parents nursing experience in using them as a support network:

'...both my parents are nurses so I have my own little sort of support network and they've obviously been through other experiences, so I can always chat to them about my thoughts and feelings and things.' (participant 12 Community p.11)

The implication from participant 10 is that support at home is more their ability to accommodate the emotional state in which she arrives after work:

'Sometimes I'll go home and talk to my husband, but I think sometimes I go home and am quiet, or I'm angry with everybody' (participant 10 Community p.14-15)

Humour can be used to protect, to maintain an appropriate distance (Davies and O’Berle, 1990). Participant 8 made a collective claim that ‘loads of people’ in palliative care rely on a sense of humour to maintain a balanced perspective. He explains how he works at fuelling his humour at home with friends as a means of completely ‘being’ himself:

‘But I think one thing that’s massively important, and I think loads of people would tell you this in palliative care, is to have a sense of humour...If you haven’t got a sense of humour you’re doomed’...‘I try and watch comedies as much as I can, and have a really good laugh, because I think that just releases so many good chemicals and they’re so good for you. And to be with friends who you can just be completely yourself with, be the biggest fool, and just have a really good laugh, a real belly laugh’ (participant 8 Hospice p.21)

His claim is supported by respondent 10, who after describing palliative patient scenarios she had experienced believed that to survive it was important to partake in activities to lighten mood:

‘I try and do something light-hearted, watch some silly television programme or read a book, but nothing... something quite light-hearted really, trying to change my mood. That’s what I tend to do. If I want to read a book or watch TV it’s got to have a happy ending!’ (participant 10 Community p.15)

6.4c Summary: being a “spiritual carer”

In choosing how we are with, and how we treat others, we reflect our potential for being spiritual; it is reflected in the way we provide care. Establishing a rapport with patients is fundamental to identifying their needs. Communication that reflects spiritual care is ‘connected’, in that, it is patient focused and triggered by the emotional insight of the carer, which enables the carer to identify with the sufferer. Caring conversation is generally the preferred means of participants’ exploring the patient’s spiritual needs. However, one participant felt a written document including guiding questions was useful in initiating a spiritual assessment. Verbal communication was not always considered necessary in establishing a rapport, but the supportive presence of just sitting with a patient could induce sufficient confidence to

enable them to begin to share their worst fears. The process of active listening facilitates the listener's potential in reaching for meaning to gain a deeper understanding of need, and so, contributes to a better interpretation of what is being said. Hence, active listening is a means of sharing oneself and can both facilitate identifying spiritual need and be a source of spiritual care. This is reflected in participant comments that suggest the need to 'give' or 'find' time to ensure patients had time to 'talk'. Participants' spiritual well being is maintained in a number of ways. These include solitary activities, the distraction of home life, a friend or relative's 'listening ear' and a sense of humour to maintain a balanced perspective.

6.5 Becoming proficient in spiritual care

'It's all about them and what they want and also their families' (participant 12 Community p.2)

Adulthood in western society is associated with a sense of control (Friedemann et al, 2002). Generations grow and are educated in a culture that values, individualism, technological and scientific advancement. Such advancement provides an increasing expectation of individual choice. Participants' experience provided examples of how spiritual care was individualised and how patients and their relatives were enabled to make real choices that were meaningful and hence facilitated coping in end of life situations. Nurses' accounts of personal loss were powerful in conveying how they had grown in the face of suffering and how this had empowered them in practice situations involving loss.

6.5a Facilitation of religious practice as a spiritual resource

'But to everyone their spirituality is a very individual component of their soul, their being' (participant 2 Hospice p.1)

Where religious practice was a component of patient spirituality there were a number of examples of nurses individualising patient access to religious ritual or service, and so, facilitating a potential means of coping. This was achieved by their negotiating and organizing skills. Patients' needs were attended to as appropriate, for example at the bedside:

'...and the young man had been Catholic so we were able to get in a priest because I think his priest had died, the one that he was very close to' (participant 5 Nursing Home p.13)

Religious needs were also attended to in the patient's home:

'...making sure that all of the things with regards to her religion and her wellbeing, because you know that's what she believes in and making sure that we could do all those things, getting priests, and you know making sure that she could have communion at home and all those sorts of things' (participant 12 Community p.3-4)

In addition, some residents in the nursing home were supported in attending a local service:

We have the local Church of England and a Baptist church come here and they do like a monthly service, so there's a service every two weeks. And then there's a few people, 3 from downstairs and 2 from upstairs who go locally to the service on Sunday, a Roman Catholic service' (participant 3 Nursing Home p 26)

Some nurses made it clear that it was important to differentiate between their own beliefs and that of their patients so that they did not impose their personal spiritual or religious stance on others in facilitating coping. This was particularly evident in community nurse responses. The importance of not proselytizing was so important to one participant that she implied that she did not address religion at all when caring for patients. Such a restricted view may well limit this nurse's ability to facilitate fulfillment of patients' religious based spiritual needs:

'Because I certainly wouldn't give any religious input to anybody, that's... as an individual... so I would never... that's not something for me to talk about' (participant 11 Community p.5)

However, others had a more balanced view and shared experiences of how they were able to facilitate religious practice for patients who had a particular faith as a means of helping them cope. Nurses who were religious themselves were aware that their faith would affect their outlook and so, almost self-

consciously, were looking for ‘the others’ outlook so their own views did not get in the way, for example:

‘Spirituality to me is about my religion...I think that probably colours my outlook a little bit. But I know lots of people don’t have religion or are not bothered by it, so I think you have to be aware that other people see things differently. And you have to go by them more and their outlook on things when you’re looking after people, you can’t impose yours, your beliefs and outlooks onto someone else.’ (participant 10 Community p.1-2)

Similarly, another community respondent describes how personal beliefs are kept to oneself and patients’ beliefs are respected:

‘I think you still keep your own beliefs and spirituality, just because they don’t (share these particular beliefs) it doesn’t affect how that patient is nursed and you certainly would not enforce your own particular beliefs on the patient’ (participant 9 Community p.5))

However, one participant employed in a nursing home described how she did not ‘inflict’ her religious beliefs on others but throughout her interview she did tend to ‘talk’ in religious terms. She seemed to lack any awareness of this tendency when she goes on to describe how she found that patients tended to ‘pick up’ on her religious faith and that this facilitated conversation about religion:

‘I’m a practicing Christian but I’ll never inflict my views on anybody else although very often they’ll pick up on it and therefore it is a topic of conversation and that really is quite helpful when you’re dealing with people who are dying’ (participant 4 Nursing Home p.1)

In facilitating patient’s religious practice, nurses’ narratives of their experience demonstrate that the patient often leads in making requests for activities that help them cope, for example:

‘I think your path’s set out for you by the patient, I think they lead, they’ll lead the way. You might be asking the right questions at the right time, but I think they’ll lead the way. They’ll let you know... I was just thinking of a past (patient) that I’ve had, (who had) a very strong belief, and yes she drove where she wanted to go and where she wanted to be and how she wanted to incorporate her spirituality into her dying’ (participant 9 Community p. 5)

On occasion nurses' accounts of events imply that they are surprised or mystified by the requests patients make although they comply without question. For example one respondent was asked to pray for a patient and was both pleased with how well it went and emotionally moved by the event:

'And anyway we started building up like a working relationship from then, and one time I went in there and she said... she asked me if I prayed and I said 'yes I do pray every night' and she asked me to pray for her. And so I sat and it's the first time I've ever prayed with somebody...and I said this prayer and it came out really good. And she was having a cry afterwards, I was having a cry afterwards, and I don't know...she just seemed more relaxed after that' (participant 3 Nursing Home p.8-9)

Another describes how she has been asked by patients to pray for them, even if they have previously had no faith in the existence of 'God'. However, this is the same respondent who lacked awareness of her tendency to 'talk' in religious terms. Continued exposure to religious 'talk' may have resulted in patient compliance to an expectation of pray rather a desire for it:

'...some...people who've not believed in God, towards the end of their lives will actually look at you and say can you pray for me' (participant 4 Nursing Home p.14)

One hospice respondent explains how she has been asked both to read the bible and pray with patients on occasion. It is not difficult to envisage the comfort such activities may offer, not only in hearing the words spoken but also possibly bringing some familiarity of worship where others read the Bible and prayers are said together:

'Well, there have been patients who've asked me to read from the Bible for them...Or when people ask you to pray with them, I mean it does happen sometimes' (participant 1 Hospice p. 6-7)

One community nurse thought it 'strange' when a patient she had known for years, and who had not appeared to be practicing a religious faith, asked her to get his bible from a cupboard. Although when describing her experience of spiritual assessment as a general issue she indicated that assessment needed to be ongoing because patient's needs change (6.4b: 102) The Bible was a school Bible which evidenced his early grounding in Christian faith. He was also

specific in the text he wanted to read which further suggested that that grounding was thorough or that he had in some way maintained his biblical knowledge throughout his life. The nurse also thought it 'strange' that he wanted to read from the book of Job which she described as 'very dark and questioning'.

'But towards the end, I suppose about three or four weeks maybe, really quite (near) to the end, (he) was insistent that the Bible was at the bedside and I'd never seen his Bible before but (it) was brought out of the cupboard and it was (an) old Bible from school...and he picked it up and read Job, you know, it seems awful but to me it's very dark and questioning' (participant 9 Community p.6)

She continued to reflect on his background, appearing to be trying to make sense of this situation herself, and recalled that his background might 'shed a little light' on that because, that was also 'strange'. Born in India he had been pressured into religion as a child and had since, at least in part, rejected that religion to make up his own mind:

'I'd known the gentleman for some time, years in fact, and you know nursed him through that coping, that acceptance of what he was going to reach and face, it was really quite bizarre. And quite young as well, so...hmm. But the background was really quite strange, it might just shed a little light on that, which is probably where it came to, was his parents were missionaries in India and he was born in India and lived in India and had said at one point that he had the belief but he felt pressurised as a child and lost part of his religion because it was enforced on him, I think maybe he felt he needed to make his own mind up. So (he) wasn't actually practicing as far as I knew...had just brought it up on initial assessment and then that was gone... for a couple of years...' (participant 9 Community p.6-7)

In the same way as most of the participants were introduced to religion in their childhood and moved away from overt practice in their youth, only for some to later rediscover their faith, it is not unreasonable to consider that some patients may have done exactly the same particularly in the light of Culliford's consideration of this phenomena (6.3a: 80). Also, this man was dying and may well have felt that his situation was dark and it was one which might well engender questioning. Bible stories often reflect life situations and can offer hope for those who have faith. Job's faith saw him through difficulty so that

his 'latter days were more than his beginning' (Job 42:12). Hence, although perhaps not understanding her patient's choice, in complying with his request she may well have facilitated his coping.

In other ways, nurses lead in the identification and means of fulfilling patients' needs of religious practice. One participant 'checked out' the boundaries of her personal ability to meet a patient's need by looking to the Chaplain for support:

'And sometimes people do actually ask you things sort of about God or relating to - I talk about Christian religion here (it) is the only thing I experience here at work- and people might ask questions which are about the existence of God... once somebody had read this chapter from the Bible and I felt I was able to answer but also sort of went to the Chaplain...I just think that surely he's far better than I am obviously to deal with that, and possibly probe further if that is the right word.' (participant 1 Hospice p.7)

Another respondent intentionally raised the issue of religious practice when in conversation with residents on their admission to the nursing home. Once again this was the respondent who was unaware that she 'talked' in religious terms. Her rationale for being so direct in enquiry regarding religious needs was that she anticipated that many residents may have a view on religious practice due to their generation and not acknowledging this on admission could limit identifying their individual needs in this respect:

'...and I talk to them and say you know are you a church goer, do you have contact with the church, and a lot of them do because a lot of them are of the generation where they've spent their lives in a church scenario. Once they come in here that makes it very difficult because they have that loss of freedom, loss of everything, loss of individuality. And so I go through with them what it means coming here and what can I do to help, and I'll often arrange whatever they want to come and visit them. If they have no church but they'd like to see a minister we usually get the chap in from Age... you know, the Church of England, if it's Baptist I'll get a Baptist minister. You know, I will always try and find somebody appropriate' (participant 4 Nursing Home p.13)

6.5b Empowerment of patients

Hope is an integral part of spirituality and is a powerful coping mechanism in times of duress. A dominant component of hope is the personal dimension, or

spirit of hope that involves meaning associated with a sense of the possible or feeling of empowerment (Nekolaichuk et al, 1999). Any sense of loss of value potentially challenges hope. Hence, individuals whose health is declining or who are informed of the terminal nature of their condition can feel ‘written off’ or valueless and lose hope (Flemming, 1997). This is exacerbated as the need to relinquish significant roles related to ‘who they were’ is increasingly associated with dependence on others. Respondents’ accounts of their experiences include several examples of such situations. Each respondent’s example differed as did the means of helping patients, but they reflected a fundamental understanding of the value of facilitating patient empowerment by giving or allowing them real choice and hence control over the measures they could take in coping with their situation.

The difficulty for patients in expressing themselves in relation to their own end of life care issues was touched on by one nurse. She implies how liberating choosing to join the hospice’s creative writing group was for one particular patient and relative. Writing not only helped them express themselves but in so doing, helped them face and deal with their issues.

*‘...they have art group here in day therapy ... and... creative writing groups ... I remember with the first creative writing group...this book was produced...and I have actually spoken to a patient and husband of a patient who joined that, and say how positive it was...how it helped them (in)...expressing and therefore facing and dealing with certain issues...and...the art group...people do find it positive actually making or creating art themselves’
(participant 1 Hospice p.19)*

Similarly, art provides a way of exploring the deeper meaning of being, of understanding existential issues related to dying that are not easily expressed in words (Sheldon, 1997). Participant 1 was aware how positive patients’ found expressing themselves in the creation of artwork:

‘...they say that by being involved in something like that it takes their mind off things completely, which I suppose is very important, I suppose an incurable illness is something that weighs on your mind all the time, so they do say “it really takes my mind off something”, and then, “being able to share it with others” is something that is said I like to think there may be something a bit deeper as well that they

can't explain in words, or I can't put in words!' (participant 1 Hospice p19-20)

Another scenario concerned a young women who was dying and found it difficult coming to terms with the loss of her role as a mother. She repeatedly expressed her feelings of complete failure in not being able to take care of her boys. However, she was encouraged to create memory boxes for her sons which would help them remember their relationship with her after her death (Holloway, 2007). On the occasions she was well enough to return home for a day she was able to pick up items of her own choosing for this endeavour. In this small way she was still able to 'do' something for her boys and the nursing staff felt this helped her come to terms with her situation:

'I'm thinking of a young mother and two boys. And the loss of her role as a mum...it affected her tremendously. She used to talk about it to us and various members of staff, whoever was with her really, caring for her. She just used to talk about how she couldn't do these things for the boys any longer and she just felt a complete failure. And it hurt...I think it probably hurt her more than anything...I think putting together memory boxes for her boys helped her come to terms with that, because she was once again doing something for them...I don't think she ever completed them but...she went home on day leave from here more than once and I think when she was home she picked up things from the house and put them in these memory boxes for the boys. And we felt that compensated a little for the losses she was feeling about not being able to do anything for them' (participant 2 Hospice p.16-17)

A further example was a woman who had been beautiful and who struggled to deal with the change in her appearance due to the side effects of the medication she had to take due to her illness. She also had a young son who drew a picture of how he saw his 'mum'. This drawing provided her with an alternative perspective in reminding her of the 'self' that was not lost, her enduring role as a mother. She used this drawing as a source of coping by choosing to cover her mirror with it and, in this way had a more positive view of her 'self':

'...I remember a lady here...she was, you know, stunningly beautiful before she was ill and took loads of steroids (due to) the illness, and from when she was admitted the first time to when she was admitted the second time you wouldn't

have recognised her, nobody would have recognised her. And for her...well for anyone, but particularly because of the type of person she was, that was hugely difficult to deal with so she couldn't look in the mirror, because she'd lost the person that she was she wouldn't look in the mirror. So her little boy drew a picture of her and how he saw her and she stuck that on the mirror so that when she looked at it, that's what she saw was how he saw her, not what she looked like now' (participant 6 Hospice p.9)

These examples have all been taken from the experience of nurses working in a hospice environment. The hospice in question benefits from a number of resources that include the provision of therapies such as art and creative writing. They also include a family support service that would have been available to help both the children, and parents, involved in the latter two scenarios. The availability of these resources clearly facilitated the hospice nurses' empowerment of their patients.

Regardless of resources, patient empowerment was also exemplified by the experiences of some nurses in the community and nursing home environments. This was primarily by advocating for patients interest (Webb, 2000) when the choices patients had made in coping with their own death were challenged by their relatives. One example of this concerned a matter of ensuring that a patient's decision of 'how' she wanted to die was respected. The research participant, a community nurse, explained that one patient, who was an accident and emergency nursing sister, knew that she was dying and was very prepared and organised in what she wanted. Her decisions were based on her strong religious faith and her professional understanding of medication for management of her symptoms. However, her husband, who was an accident and emergency medical consultant, wanted her life to be prolonged and pressed for more active medical intervention. The community nurse showed an understanding of the consultants 'mindset':

'...she was an A&E sister...And she had a very strong faith herself, a strong Catholic faith, she knew she was dying. She had everything prepared, she had organised everything, we did what she wanted, she had the drugs that she felt she needed, she had the care she felt she needed, but it was quite hard on a couple of occasions. One particular occasion when her husband cornered me in the kitchen because I was

getting her syringe driver drugs ready, and he was an A&E consultant, and I think looking after somebody in their terminal stages takes (a) different mindset to an A&E consultant, because we know we're not going to make somebody better, our aim is to provide somebody with a good death. The death that they wanted, as pain-free as possible, and in a way that they wanted and acknowledging the fact that that's (death) going to happen. Whereas as an A&E consultant, it was also his wife so he obviously loved her dearly, (he) does not normally look after somebody who's dying, their aim is to get somebody to A&E, fix them up, get them well and send them on their way, so he was trying to make suggestions about what we should do with her drugs to make her better.' (participant 10 Community p.8-9)

The organizational structure of nursing services is hierarchical whereas doctors work in collegiate systems. Consequently, nurses may be caught in divided loyalties between patient and doctor (Jeffery, 2000). Although, 'out ranked' in professional kudos by the consultant, the nurse remained adamant in her responsibility for her patient and explained why she needed to respect her patient's choice of care as she would, presumably, to any husband.

'...(I) explained to him as best I could that if we changed the drugs to what he wanted it wouldn't alter the outcome and to remind him that was not what she wanted and we had to do what she wanted because she was our patient, and she was the main reason we were there and what she wanted was what we had to do. And that we understood that he felt hopeless and he didn't want to lose her, but perhaps he should spend some more time talking to her.' (participant 10 Community p.10)

This same participant gave another example of how a patient's choice of 'when' she would die was respected. On this occasion the patient appeared to have decided that she had had enough and wanted to die. She said she could not eat because of nausea and retching but she had never been seen to retch by anyone and so perhaps not surprisingly measures to assuage these symptoms were ineffective. Her family was frustrated by the patient's apparent determination not to eat:

'She'd decided that she'd had enough and wanted to die, but she hadn't quite reached the end stage of her life...but she was almost forcing herself to. So she was ready but her family weren't. They were finding it hard. So you had her saying that she couldn't eat, and that she's feeling nauseous

all the time. And the family are saying she is eating, there's nothing wrong. And that caused a bit of a...sort of tug between the family and the patient for us nurses, because the family were saying they want one thing and then the patient says she wants another. So you have to go with the patient, its their decision...with this particular lady we'd tried every single drug we can find to stop her feeling all this nausea and this retching but nothing seems to be working but nobody actually saw her retch at all, but she said she was doing it all the time. So I think it was her way of saying I've had enough, I don't want to eat or drink anymore, I just want to go now.' (participant 10 Community p. 13)

Patients may understand self empowerment by choosing to shorten the period they live with dying by not eating, and so hasten death. The nurse rightly understands that she needs to advocate for the patient's right to choose in a situation where the family are confrontational. However, she was also right to feel uneasy, when the patient requested opioid analgesia without any apparent symptoms of suffering pain. There is a significant ethical difference between a competent patient's right to decline health care offered (Randall and Downie, 2006) and the nurse being asked to administer medication to hasten death:

'... she told us that she was in pain and the dilemma was – I wasn't convinced she was in pain, I think she was just asking for diamorphine because she thought it might speed things along. But the dilemma is she told us she was in pain. Somebody's perception of pain is what they tell you...She was just a determined lady who'd made her mind up. And so she was going to take herself to bed and die' (participant 10 Community p.14)

Friction in families was also exemplified in the account of one respondent practicing in a nursing home. Rather than a particular patient scenario this nurse makes a general comment about the pattern of families appearing in relation to the timing of patients dying. Accepted practice allows competent patients to make their wishes regarding future treatment known by written statement or witnessed oral statements (Randall and Downie, 2006). Participant 5 sees the increased tendency for people to write down what they want as the 'means' of empowering dying residents. The implication is that by formally recording their choices while they are still well enough to speak for

themselves the dying will not be overwhelmed by their families wishes as they weaken:

'Friction between families is something that is difficult at times, you know, we have people that have been here for years, never had a visitor, then in the last days of their life there is a descent of people that you've never met before suddenly are here... It is very difficult. I think now...with more people writing out their last wills...I think residents choice, you know it will be easier for them to write down what they want before maybe it gets to that stage...I think maybe the family have to see that paper, (identifying the patients wishes) it maybe would make them think...I don't think they realise how overwhelming they're being at times' (participant 5 Nursing Home p.16-17)

6.5c Empowerment of support staff

In the nursing home environment the needs of individuals vary with some only needing supportive care. Consequently, one or two registered nurses manage a team of care assistants/support workers on each 'floor' of the nursing home. The registered nurses were aware of the need to promote and maintain awareness of whole person care, particularly among the young inexperienced support workers, for example:

'...and we have a really, really good team. And it's about the strong helping the weak. And it's very difficult, some of them are very young and you have to be really careful that looking after clients doesn't become just a routine, you know, you wash and feed and change them, wash and feed and change them, get them up, put them back to bed, wash and change them...you know, and it can become very rote' (participant 4 Nursing Home p.24)

The implication is that those made strong by knowledge or experience help those who are 'weak' in either or both. In this way the experienced can empower the novice carer to understand the importance of holistic care as the bedrock of facilitating coping.

Another nursing home respondent describes the range of skills found amongst the support staff as being very mixed. Relevant experience in end of life care is conveyed as being rather random, through personal life or past working experience. She also implies a similar awareness to that of participant 4 above, in that some support staff consider their role as one of tasks to complete rather

than having a more vocational view of caring, described below as the ‘bigger picture’:

‘I think we’ve got such a wide skill mix, we’ve got very young girls to staff of retirement age. Some have had prior experience in care homes, some haven’t. Some have had a lot of things happen through their own personal lives, whereas obviously youngsters maybe wouldn’t have been through so much that they can relate to. And it’s how they view their job role, I think some of them believe that you know, they look at their job description in black and white, they feel they’re coming in to wash people, dress people, feed people. Not all of them see the bigger picture. I’m not saying that’s through their fault but that’s through their training or their understanding of the role when they take it on’ (participant 5 Nursing Home p.5-6)

This participant goes on to acknowledge the culture shock and potential fear for inexperienced support workers in dealing with death and compares this with the inevitable preparation that all registered nurses have to undergo regarding caring for dying patients. She implies some hope for ‘change’ as training may empower all support workers to contribute more effectively in the care of the dying. The Liverpool Care Pathway that she refers to is a protocol for addressing the last days of a patient’s life (Thomas, 2003). This guidance reflects holistic hospice philosophy in attending to essential physical, psychological and spiritual needs of the dying person as well as the communication and bereavement needs of their signification others.

‘I mean they are doing the Liverpool Care (Pathway) as part of their training now here, they’ve started doing it, so perhaps it will start to change, but there is a huge difference in skills. Whereas as a nurse, when you train to be a nurse, you can’t avoid death, you know yourself you have to go... you’re going to look after people that die, you’re going to be with those relatives and you’re going to be involved in that situation and a carer, (they’ve not) necessarily ...had any prior training so they wouldn’t have been. So some of them I think maybe haven’t thought it through and realised that or they are really frightened of it themselves and they keep away’ (participant 5 Nursing Home p.6)

Another nursing home respondent described how, on occasion, she had overheard well meaning support workers offer patients empty reassurance:

'... they're really worried about something and the carer just tells them 'Oh well it'll be fine, they'll sort it out'. And you know full well they won't sort it out, because you know what the problem is, and so the person might feel that they can't discuss it, they might feel they can't. You know what I mean, you think... are they trying to sort of shut them up or are they just trying to make themselves feel better?' (participant 3 Nursing Home p.16-17)

She started to address this issue by endeavouring to empower staff by an awareness raising activity. She had studied spirituality as a perspective of health care as part of her degree programme and described at interview how she had set up a spiritual reflection group in her workplace. Attendance at this group was voluntary and was aimed primarily, but not exclusively at support staff:

'I've started addressing these sort of issues in...things like the spiritual care support reflection groups which normally get between 6 and 8 staff at a time...I tend to do like two sessions, I do like a first one where we just talk about what spirituality is and how it is relevant to our work and look at examples which I've taken from literature. And sometimes in that first session they'll start relating it to their own work, and sometimes they won't, it depends on the group you've got. And then the second group, I do this sort of like reflection of issues to do (with) their work so they have to start thinking and bringing up things and thinking along the lines of...how right was it, how wrong was it, could it have been done differently, and all that sort of thing' (participant 3 Nursing Home p.17-18)

In helping those who attended the sessions address what spirituality is and increase their awareness of how this relates to their work this practitioner empowers them to choose how they think about and approach caring for residents. In this way support workers are potentially better able to assist residents and registered nurses in their facilitation of residents' coping strategies.

6.5d Personal loss as a source of enhanced understanding and positive growth

Some nurses' personal stories reflect what Bury (2001) refers to as 'biographical disruption' (p.271) where illness or a particular traumatic event,

appears to have led to a re-examination of life issues in relation to the diagnosis of disease or the incident in question.

Participant 9, for example, described how her personal experience of loss had made her aware of how little she had really understood previously about the process of grief. She reflects on how, despite her interest in psychology and her understanding of grief theory, she had no real depth of understanding of what the phases, stages or words used to describe the process of grief meant until she lost her father. The impact of personal loss on professional perspective has been described by others (e.g. Ballhausen Footman, 1998). In this instance the nurse's professional understanding appears enriched by her personal experience:

'I think... until I lost my father I don't think I fully understood what loss and bereavement was, felt like. I've always been kind of interested in psychology if you like, and have read quite a bit on loss and bereavement. I think we were all brought up... with Kubler-Ross with her seven stages,... and I hope I remember the seven stages and going down them and thinking yes that's the reaction that she talks about, and yes that's perfectly understandable and people work that way, but until I lost my father I think I don't really... I didn't fully understand what those phases were, when she talks about guilt and bargaining and anger and denial and all of those things, I think they were just words that you could pick out in a dictionary and look to see what the meaning was, but until you've actually experienced it yourself... I don't think I had any depth to my knowledge other than having read research papers or books on loss and bereavement or attended hospice lectures and that sort of thing. So I think for me, I very much had to experience it and it was quite late in life,... because I didn't really know my grandparents and was lucky enough not to have lost anybody near and dear until I was sort of 50 really. Well, mid-40s. So it's personal experience of loss that gave me depth to maybe some of the knowledge that I had' (participant 9 Community p.8)

Similarly, participant 2 describes how her personal encounter with grief following the loss of her son partly accounts for her taking a nursing post in a hospice. She uses metaphor to describe the impact of her son's suicide, and tries to make sense of the situation in asking 'why':

'And that threw my world just up in the air and it came crashing down in bits and pieces... from thinking that I

couldn't go on and why had this happened to me, to us as a family, I - from that very dark place – with the support of both family and friends, and I have to say my faith, and my attitude to life that you can't be in control of other people...And at the time I asked all these questions, why? What have I done wrong? I wasn't a good enough mother? 9½ years later I'm strong again, and during... about six months after James died I sort of decided that I had to get on with my life and what was I going to do with it, I didn't want to retire, I wanted to carry on nursing, and that's when I saw an advert for a post at the ... hospice as a staff nurse. And when the hospice opened I thought oh I'd like to work there, and I felt this was my opportunity. Because I had (a) close bereavement I was advised not to start until 12 months after my bereavement and in fact I started there 10 months after my bereavement' (participant 2 Hospice p.6)

This respondent appears to exemplify how emotional response to loss, such as anger, although potentially destructive, can also energise individuals into positive activities that are a direct result of the loss (Sheldon, 1997). She has, for example, come to regard the tragedy of the loss of her son as one of growth, in that it has opened opportunities that have enriched her life and professional practice, for example, she feels able to offer support through a national support line to others bereaved by suicide.

Also, she feels she is able to be more empathetic towards patients and their families who have had to cope with loss and bereavement. In an interpretative phenomenological study focused on the experience of nine older adult Christians' search for meaning following the loss of their partners Golsworthy and Coyle (1999) also found that participants referred to '*an enhanced capacity for empathy and understanding of others*' (p.34).

In addition, knowing that three people have benefited from the donation of her son's organs has helped this participant make sense of personal tragedy:

'And my experience with losing my son really gave me a lot of empathy towards the families, the patients and families I was looking after. And spiritually I felt that this is one good thing that has come out of losing a son - which one would never ever want to. And other good things have happened as a result of losing James which have enriched my life. One of those being... we were able to donate some of his organs

when he died and three people have got new life because of the loss of his life, which I'm eternally grateful for, because it has given me a very positive aspect to my bereavement and my grief. And latterly, the last three years, I've been supporting other people who have or are trying to survive a bereavement by suicide, by manning a national support helpline – the acronym is SOBS – it's Survivors of Bereavement by Suicide' (participant 2 Hospice p.7)

The same respondent describes how such life experience helps the development and growth of the spiritual self as a source of strength and a resource which better enables us to support others:

'I think spirituality develops within a person as that person grows in age and life experience. I think it changes through life and life's experience... it's how we see life and how we get through life's challenges whether they're good or not so good. It's our strength, which enables us to cope with different situations. And also it's a strength that helps us help other people, because of our own life experience, and how those experiences have helped us develop our spirituality' (participant 2 Hospice p.1-2)

6.5e Summary; becoming proficient in spiritual care

Where religious practice was a component of patient spirituality nurses endeavoured to individualise patient access to religious ritual or service. Hope is an integral part of spirituality and involves meaning associated with a sense of the possible or feeling of empowerment. In facilitating patient empowerment, or advocating for their right to make choices, participants provided patients with a measure of control in coping with their situation. Examples included art as a means of understanding existential issues that are not easily expressed in words, and the encouragement of a mother to create memory boxes for her sons which would help them remember their relationship with her. Advocacy was necessary when the choices patients had made in coping with their own death were challenged by their relatives. Inexperienced support workers also needed to be empowered to cope with the culture shock and fear of dealing with death, and to understand that empty reassurance was inappropriate in these situations. The experience of personal loss appears particularly powerful in strengthening nurses' empathy for patients who are struggling to 'making sense of', and cope, with loss.

6.6 Belonging as the means of maintaining spiritual integrity

'...so you have to think about... who can help' (participant 11 Community p.8)

In the same way as developing a rapport with patients is important for nurses to both assess and provide spiritual care, the rapport between team members and the team and its' organisation's management is important in developing meaningful relationships and purpose in the work environment. In this sense, right relationships provide a spiritually supportive ambience in the workplace (Wright, 2006). Spiritually supportive work environments facilitate both informal support within teams, and nurses accessing support in the provision of care that exceeds their boundaries of experience. This may be directly for patients, indirectly in helping nurses care for patients, for relatives or by relatives. Similarly, formal support for nurses, particularly where there is an identified need, is inherently spiritual, in helping nurses make sense of difficult situations.

6.6a Accessing support for patient care

Interview accounts included a number of examples of situations in which patients needed additional support that was arranged or facilitated by the nurses rather than provided by them. One respondent from the hospice, for example, described the sort of situation that would generally warrant nurses to refer a patient for counsellor support. However, although she implied that she agreed that patients coming to terms with, or wanting to talk about their impending death would benefit from talking to these professionals, her personal preference for referral in the first instance was for pastoral support from the Chaplain:

'I think sometimes, perhaps, people sort of coming to terms with or wanting to talk about their impending death...if we feel - sorry I'm now sort of talking about 'we' as nursing staff in general in the hospice - often refer to the family support team, which may consist of counsellors. Although, I personally, even if it's non-religious, I myself would probably speak to the Chaplain first of all because he's also very good in non-religious spiritual care.' (participant 1 Hospice p.10)

A different perspective on support was given by a respondent practicing in the nursing home who described situations in which the nurses needed support

from others to help them with patients who are mentally ill. The first example she gave was where the challenge for staff was helping a patient who had schizophrenia to stay calm. They were resourceful in finding a volunteer from a local church to spend time with her. As the patient was religious this form of companionship would have provided familiarity and the comfort of an additional person to talk to. In addition they sought professional support in arranging for a Community Psychiatric Nurse to visit regularly to help staff manage the patient's particular mental health needs within what was a general practice environment:

'I remember a woman who...it was quite difficult...she had schizophrenia and she was here because she also had physical diseases as well. And she needed someone to talk to a lot of the time to keep her calm to stop her from going where they shouldn't do and that sort of thing. And hence, because the carers found her quite difficult to manage, the trained nurses were spending a lot of their time with her and so, because like we were spending so much time with her it was taking time away from other people who needed us. And the nurses could see there was a need to try and get outside support for her. She was a religious lady, we ended up being able to get her a volunteer from the local church who used to come and visit. And then we also got a CPN to come and visit her ...regularly as well. And even though it was still quite difficult to manage her within the home in the time constraints we had made it easier and she was more calmer' (participant 3 Nursing Home p.2)

A second patient scenario, described by the same respondent, as not being as 'drastic' still indicates the additional time needed to support patients who are mentally ill. This patient was depressed and although her week was interspersed with visits and social activities from outside the nursing home, the patient's mood was very low in those periods when she was not being visited. The nurse's account also indicates how difficult it is to encourage hope, when a patient's memory is unreliable and limits their ability to 'look forward':

'...and I think of a lady who's still with us, and I mean she is very low in mood a lot of the time...you go in to see her to do what you need to do and she'll sort of say something like she needs help from carers to do this, that and the other, but she doesn't want to press her buzzer because she's being a nuisance. And I don't know, she... ...she's obviously

depressed, she's on antidepressants which haven't made that much of a difference...she's got a visitor who takes her to the hospice service once a week, and she has a daughter in law – her family don't see her because they can't cope with her being in a nursing home...her daughter in law visits a couple of times a week. She works full time and so she can't really manage to do any more, and then she (the patient) has a friend who visits once a fortnight. I mean its all so difficult for her, with this disease she's got, her memory isn't very good so its difficult to try and orientate her to look forward. You come in the morning and it's 'oh, what's going on today'. She'll say what day it is, sometimes it'll be right, sometimes it won't. It's very difficult because even if, like, she's got a week where she's doing something, social activities or visitors every day, she'll still have a morning where she's really low because nobody comes to visit her, she doesn't do nothing' (participant 3 Nursing Home p.3-4)

Similarly, a hospice nurse describes how her team should have been much more assertive in involving more professional support from mental health services than they had done in one particular situation. The patient had been admitted for symptom control but remained in the hospice for eight months. His symptoms were controlled relatively quickly, in a couple of weeks, but her experience left her with a sense of her team being abandoned with a patient who had mental health care needs that they did not have the experience to deal with:

'...it was an ongoing situation and it was a young man who was forty five and he had a very rare cancer but he also had been a paranoid schizophrenic since he was eighteen. And he had been looked after by the mental health team since eighteen years old. (A) Very intelligent man, very intelligent man. And he came to us for symptom control...and ended up being with us for eight months. And it was an incredibly difficult eight months. And I feel that we weren't supported by the psychiatric team. His cancer was not his main problem, his paranoid schizophrenia was. And we're not mentally trained, and on hindsight I think we should have been much more assertive as a team in the very beginning and got the psychiatric team on board to support us and to support him' (participant 2 Hospice p.20-21)

The support networks available for patients in community and their benefits are outlined by respondent 9. However, she goes on to describe that personal belief may provide an inherent source of support for patients who are

philosophical in understanding death as a natural progression of living, and that it is not always access to support in relation to death itself that patients need, but more a case of support for the process of dying:

'There's definitely support networks from our palliative care team, you know, MacMillan Nurses and other alternative kind of therapies and things, I think there's lots of support goes on there, meeting people with, you know, similar diagnosis, prognosis, that all... they're all things that people draw on for support, not... I could say not spiritual, I didn't mean not spirituality but I was going to say... all some people need maybe is their spirituality, their belief in this is life, this is the natural progression, however I die I'm meant to die at the end of the day and they maybe don't... I don't know, maybe they don't have that adjustment to acceptance because it's already inherent in them if you know what I mean? People say no, it's got to happen and however it happens it's not the actual (death) happening it's maybe the process (of dying)' (participant 9 Community p.11)

Sheldon (1998) outlines a number of factors around the time of death that are associated with a poor outcome of bereavement for relatives and significant others. Consequently support that spans the event of death is considered beneficial for the bereaved (Currer, 2009), an example of which is given by participant 5 when she describes a scenario in which a 39 year old man suffering from multiple sclerosis was admitted to the nursing home to die. His mother was distraught. Additional nursing services during the terminal phase of her son's life also provided increased support for the mother. A responsive GP and advice from MacMillan services enhanced support further:

'We had a young man die here...he was thirty nine and his mum really needed a lot of support, it was the second child she was about to lose...they let us have two trained nurses on the floor while he was terminally ill for a few days. So you've got more people to support his mum, to go in there, so somebody was always with her. We have used the MacMillan nurses from the hospice for advice, although we're quite confident in defining our own care to be honest. But the resource is there. The GP, our GP at the time, was very good, he'd come in daily' (participant 5 Nursing Home p.8-9)

Also, following her son's death additional resources were used to enhance her last memory of her son and for her support in bereavement:

'We had an aromatherapist working here then who came in after he'd passed away and laid him out all very nicely and made the room look very nice, so we were able to do that for her (his mother). And we organized support for her afterwards through the MacMillan nurses as well' (participant 5 Nursing Home p.13)

Another example of a scenario when additional support at the time of bereavement was beneficial was described by participant 9. One family was at a complete loss as to what to do following the death of their mother at home. They felt unable to call the funeral director themselves and the district nursing sister bizarrely became the 'go between' in a three way conversation between the relatives and the funeral director. They did know however, that they had not had enough time with their mother and wanted the collection of her body delayed. The nurse complied with negotiating arrangements that allowed the family to cope with their loss in their own way. Her actions were perceived as sensitive support by the family:

'They were at a complete loss as to what happened next...I do remember having to say to them we need a funeral director and we need to phone and...etc etc...And was telling them all about this funeral director and things and they were taking it all on board, but they then pushed it all back at me 'could you do it, we can't do it'. And I remember thinking these are mature women and a mature husband, intelligent people, but they couldn't pick up the phone, so I remember ringing... and then sort of having this 3-way phone conversation with the funeral director and the family...And they clearly did not want that body removed. And they said yes, they realised it had to happen but they hadn't had long enough...they did know how to deal with their loss but not in the way that, if you like, as a professional I needed it to be dealt with...Because I'd always thought... although I'd never put a time frame on it, but I thought perhaps these days people want the job done... I don't know. It was really quite bizarre... we did agree on a time, they ordered the body to be removed at night as well, not during daytime hours...I don't know why, I didn't really explore that' (participant 9 Community p.14-15)

The nurse went on to explain how this event, which she had found bizarre at the time and one that she had not really understood, had been a lesson for her in raising awareness of how she had assumed relatives would take similar

action to cope with bereavement, when in fact facilitating their individual coping strategies was the most effective form of support:

'But I have to say I did get home late, probably about 2 hours, but I remember going home thinking that was quite a good job done really...I had the (most) wonderful memorable letter of thanks that I've ever received in the whole of my nursing career... from that family in that they used words like 'sensitive' and 'calmness' and I just thought well... that was a bit of a learning curve for me too... and I keep it on me...because it was just... it pulled me up, I think. Because I obviously had some assumptions didn't I, you know, once death occurs the body is removed and people kind of get on with it, but they needed to get on with it their way...Even though I kind of couldn't understand it at the time, but isn't that what it's about, you know, we're all individuals aren't we and you know people if that's what they want, then if it's humanly possible then that's hopefully what they get, because (death) it's quite an event'(participant 9 Community p.15-16)

Family relationships played a significant role in supporting patients in a number of respondents' accounts. One respondent employed in a nursing home describes using the supportive relationships within families who are 'on-side' as a strategy to help clients cope with their situation:

'And if you've got family that's what I call 'on-side' then you use them, you know, don't abuse them but you actually use that relationship to help the client to cope with the situation' (participant 4 Nursing Home p.17)

More specifically, three scenarios, all given by hospice nurses, described how a particular member of a patient's family helped them deal with unfinished business. In the first instance, the hospice staff, intuitively aware that a patient was troubled, spoke to her family and eventually managed to elicit details of estrangement between the patient and her brother. When asked, the patient was keen to see her brother. The brother agreed to see her and so appeased his sister's need for reconciliation before she died:

'And we just felt there was something troubling her that we hadn't recognised...And we spoke to her family about it...they eventually said there is someone that mum hasn't seen for many years, and they told us about the brother and that they'd parted on bad terms, and the family didn't feel that they could talk to her about it. So we said is it alright if we talk to her about it, so they agreed...I...had some time

with her on my own and I broached the subject, and she just started crying, and I just let her cry. And I said would you like us to try and contact your brother and she said “oh yes please”. And the relief in her voice was just – just said it all...we contacted the brother and he came in and it was a very emotional reunion and she died the next day...in peace’ (participant 2 Hospice p.13-14)

A second example was described by a nurse who noticed a marked change in the mood of a patient in his care. The nurse persevered in investigating the cause and finally finding that the patient wanted to see his daughter as a matter of urgency. The patient’s meeting with his daughter was lengthy and upsetting for both of them but afterwards he was no longer troubled, and when her father died his daughter voiced her appreciation of the nurse’s facilitation of the conversation that addressed what was clearly a significant issue for them both and one of spiritual distress for the patient:

‘...there was a gentleman who I remember one morning, normally quite a jolly and happy go lucky chap, but this morning he just seemed really down and quiet ... I would say possibly even tormented by something... We went through everything and there were no symptoms that could account for...the way he was looking. And so I said is there something on your mind? And he didn’t say anything he just kept quiet which obviously meant that there was something on his mind. And I said I’m happy to hear what you say, you don’t have to say anything but I’m quite happy to just talk to you about it. And he said I need to see my daughter, and I said “ok would you like me to contact your daughter” and he said “ yes I want to see her today, its really important”...so I phoned his daughter and said he’s a little bit down and he wants to see you, its quite important so that afternoon she came. He was in a side room so I took her in there and they had about one and a half hours together. And eventually she came out ...obviously in tears... and he’d obviously been in tears and been really upset, but the torment was gone...And when he died...she thanked me for calling her in, she didn’t say what it was about or anything, but it was a very significant conversation they’d had and she felt I was able to facilitate that. So I thought that, for me, was a patient in spiritual distress at that point and by doing something very simple – all I could do was just arrange something to happen’ (participant 8 Hospice p.8-9)

The third example differed in that the patient, who was very agitated and described by the respondent as actively dying, was not reticent about his need,

which was to visit his home because there were things he needed to do. He was also very specific in that he did not want to go with his daughters but with one of his sons in laws. They were a supportive family and arranged the visit as he requested. The impact was a marked change in that he returned to die in a much more relaxed frame of mind:

'We had a gentleman once who was clearly very, very unwell and ...actively dying, who was absolutely adamant he was going home one morning, not to stay at home, just for a visit home because there were things he needed to do. So we talked to him about it and phoned the two daughters and two sons in law...and said your dad wants to, he's absolutely adamant, he's getting himself out of bed and getting ready to go and he really needs to. So they said oh well we will organise it, come over to fetch him and bring him home. But he wanted to go home with one of the son in laws and not the daughters, whatever it was he wanted to do at home it was really important to him...he wanted a man to go and deal with it with him, and I think to be honest he went home to put some affairs in order, because he came back and was a different person, completely settled, and the daughters even said it, that whatever it was he'd needed to do, it completely settled him. So he went from being quite agitated mentally to coming back and being completely relaxed, which the family appreciated as well' (participant 7 Hospice p.5)

Two examples from respondents working in the nursing home environment involved accessing support to arrange visits by residents to help them try to come to terms with their situations of loss. Both examples, in different ways, involved each resident working through upset rather than achieving the tranquility that so benefited the hospice patients. The first example concerns a resident whose husband had died previously in the hospice situated opposite the nursing home she was in. She wanted to visit the hospice and afterwards was also visited by a member of the hospice staff. Regardless, whether it reminded her of her own mortality or the trauma of loss associated with her bereavement, she remained unhappy with living so close to the place of her husband's death and was moved to another home:

'...I'd been here for a few months and...talking...with her, she came out with...her husband had died over at the hospice...and she actually asked to go over and visit the hospice...because she wanted to see the place again...She went with her family so maybe she explained more to her

family...Anyway...she couldn't stand the thought of being near the place where he died. We got someone from the hospice to come over and talk to her...and she ended up moving. So that was right for her' (participant 3 Nursing Home p.14)

The second example entailed accessing support via the care manager for a resident to visit the bungalow she had lost when she moved into the nursing home. It was not until she went back to what was her home that she realized it was no longer hers:

'We had a lady that was very upset about losing her bungalow. And in the end, through the care manager...she actually went back to see this bungalow, they had her outside the bungalow and she realised it was no longer hers. It was very hard, upsetting work' (participant 5 Nursing Home p.17-18)

6.6b Informal support for nurses

A shared value system that invests meaning and direction in care is understood to be the key to the ability to work long-term in environments involving recurrent exposure to loss (McNamara et al, 1995). This shared value system drives work ethos and understanding of what is meant by having done a good job. If this is the case, it is not surprising that most participants chose to look to their immediate or wider team members for informal support at work and found this particularly beneficial. Such informal support is often spontaneous coming from instinctual awareness of need by those giving the support. This is due to their own past experience of similar situations or their having to cope with current dire circumstances alongside colleagues, and so in that sense 'being in this together'.

The means and nature of support valued to some extent was linked to practice context, for example nurses working in the hospice environment spoke of the ways in which support was generally available within the team. This was explained by one participant as being related to the nature of the team. Nurses who are able to 'stay' the course of palliative working environments were considered to collectively imbue an ambience of support, in that support

‘bounces off staff’ without them needing to ask ‘what’s the matter’?. They also ‘look out for staff’ who are know to be dealing with complex care needs:

‘But the team here, they really are excellent...generally speaking, once you start here, you either realise palliative care isn’t for you or you stay and there’s lots of us that have been here for a long time. And it’s something that bounces off the staff and that you know you are in a supportive environment and you don’t need to say to somebody, what’s the matter? What’s happened? You just instinctively know that something isn’t right. And by (the) nature of our handovers and getting to know our patients we know, well we don’t know but have an idea of the difficulties that we can encounter with different patients and families and, if a member of staff is looking after a patient with a complex family then we know during the day to look out for them and just to keep an ear open....And our pink room-our office, you know behind closed doors – we let off steam, and we sort of pass things amongst ourselves, you know, to get it off our chests and to get back to a good place,’ (participant 2 Hospice p.18-19)

The tendency for the hospice team to ‘look out for each other’ was reiterated by another respondent who emphasised the importance of knowing ‘what’s going on’ so that colleagues are protected from being in a difficult situation for too long:

‘...it certainly is here anyway. It’s very supportive and we all know which situations are difficult and we all look out for each other, so we might also...if someone’s spent a long time in a difficult situation then someone might take over and give you a break. Yes, and being aware of what’s going on. I think people are very good at that here to be honest. Yes, on the whole that’s how it works’ (participant 7 Hospice p.15)

Another hospice nurse’s description of informal support reflects what it is they need support with. In having to manage their emotions in the face of patient and relative distress, informal support within the team is taken to mean ensuring staff are aware of how they feel, and that they have the opportunity to express that in what ever way is most appropriate for them:

‘...being in touch with your feelings, I think the worst thing you can do in this job is to bury it and just ignore it, you’ve got to reflect on those feelings and be in touch with those feelings and find ways of expressing them, but quite often because you’re a member of staff there’s that sense that you’ve got to be coping and getting on...you can’t be

showing your feelings to relatives but somehow you do need to do that in an appropriate way and making sure that there is a facility to be able to do that. And I think with staff it's about supporting each other and allowing each other to cry if we need to...' (participant 8 Hospice p.17)

The centrality of a sense of team as a creation of self empowering support is also reflected by most of the community nurse respondents. Here, 'banter' is the style of communication for a diversity of nurses to share personal 'stuff':

'and the girls I think also feel...that we have each other in here and we're quite diverse really, some who're thinking of retiring down to...a staff nurse who's (recently qualified) and has been in community for about a year now. So we're quite diverse but we all have our own experiences, I think we all draw on that. There's a time ...you know there's good bantering there and there's lots of personal stuff but I think if there was...I think we're quite perceptive to the team, the team's wants and needs...' (participant 9 Community p.19))

Such talk is located 'back at the office' and helps keep troubled feelings in perspective:

'...we come back to the office and talk to one another and I think that's a huge benefit, to talk to one another about things and our worries, because it helps to put everything into perspective.' (participant 10 Community p. 14)

One of the younger members of the team, who had only been working in the community for a year, had clearly already developed a strong sense of team as a resource to help her with emotional challenges:

'...I have a great team here so I know that if any thing upset or bothered me we could all talk about it...' (participant 12 Community p.11)

Only respondent 11 made no mention of informal support available in the community team. Also a younger member of the team, she describes how when things are hard she takes her thoughts home or tries not to think about it:

'I think it is hard sometimes. You do go home and think about things and think that's really quite awful and how depressing and how sad it is. But then that sort of makes you even worse...and then sometimes I just try not to think about it' (participant 11 Community p.10)

Her explanation for this seems to reflect a measure of what is 'hard' being on a spectrum from what she can manage herself to when she needs the support of others. In her previous hospital posts, when she would have been recently qualified and so less experienced, she had found the acute situations she faced much more upsetting than her current experiences in community practice. Her description infers that she has sought the support of others in the past and therefore knows when it is important for her to do this:

'I think that's probably more down to me, I sometimes sort of... I don't know dwell on things myself rather than share, so... if that's the mood that I'm in... I think less so here, but back in the hospital a lot more things happened that would upset me a lot more that I'd seen and talking to colleagues back then is probably what I would do because they understand. So that generally is how I would do with it if I was ready to talk to anybody' (participant 11 Community p.10-11)

Other than the general support within teams there were a couple of exemplars where respondents addressed providing support for team members or having support provided for them. One example was a sister in the nursing home who described how informal support is provided for staff in response to the death of a resident they have known for a long time. She gives staff the opportunity to choose to express how they feel including the option to view the deceased resident if they want to say a final goodbye. In addition she offers her personal support in inviting support workers to help her perform the final act of care, in laying the patient out, and perhaps, in this way is giving them the opportunity to face any potential fear they may have in dealing with the dead in a supportive setting:

'...you try and speak to all the staff if someone dies, and we've had residents that have been here for years so obviously you've got to give the staff a chance to express how they feel about that, if you're looking after someone for years and then they die, it's picking (that) up isn't it and giving them the opportunity, saying, look if you haven't done this before, if you want to go in and do last offices with me you can, but at the same time you can't force someone to do that, you've got to be sensitive, they maybe might not want to do that. And we have had people die here and they've been waiting to go to the undertakers, we've had loads of staff...go into to the room to say goodbye to them...' (participant 5 Nursing Home p.7)

The same nurse also valued informal support from her own manager. She had cared for a young man of thirty nine who was dying and whose mother needed a great deal of support. The nurse's manager took the time to ask how she was after dealing with this death and to support her. In this way her account of her experience reflected the cascade of impromptu informal support both provided by her for immediate colleagues and for her from the wider staffing of the nursing home:

'The managers are pretty good here, I mean my manager... found time to come and speak to me afterwards and say to me are you ok and to support me' (participant 5 Nursing Home p.9)

Another example was a manager in the hospice who chose to draw on informal support on a day to day basis. She explained that she relied on the reciprocal support of nurses she had a particular rapport with in that she could relate to them. This mutuality of support that overrides hierarchy reflects a response to human need in coping with recurrent loss:

'...I think even though you're managing a team below you, there probably are still certain people that you can relate to...well it is a mutual support, even though you're managing them, at times like that you still draw on each other and support each other because you couldn't do it, if you didn't, if you just took it all away to yourself...so on a day to day basis- I would support them and they would support me...' (participant 6 Hospice p.12)

Two respondents also chose specific sources of support that were available informally, but not within their immediate team. Peer support is a generic term in which people meet regularly to help each other develop personally and professionally. This support is self generating and self renewing (Heron, 1999). Participant 3, a ward manager in the nursing home, arranged to participate in peer supervision with another nurse who worked on a different floor and who she felt had similar values to her own. Meetings appeared to be arranged on an 'as necessary' basis and allowed them both to 'talk things through' and pass any issues 'by each other':

'I've got a nurse who I do like peer supervision with, who works upstairs, and we'll meet up. Sometimes we'll have

periods where we'll meet once a month and then sometimes we won't have it for a few months. So we meet up together and sort of talk things through...I'd been working here for over a year and obviously you get a lot of stuff going on and I think ...I mean it wasn't until I had been here like three or four years that I really started getting to know the staff. But she was a nurse who...I mean this nurse is on the floor so if you've got an issue you'll get together to discuss things like do I need to call a doctor, do I need to do this sort of thing... ...and you'll pass it by each other. And she was a nurse who seemed to be close to the values that I had' (participant 3 Nursing Home p.22-24)

Another respondent, who was a district nursing sister and leader of the community nursing team explained that of the six surgeries that she covered one felt particularly supportive. The surgery in question was founded on a Christian ethos and conveyed the sense of working within a family. The surgery had its own pastor who is available to talk through problems. She very much valued feeling part of this surgery, in just belonging:

'One of the surgeries I work for has a very strong Christian foundation and it's like working in a family so I think I've drawn a lot from there. We have our own pastor, one of the GP's husbands, if we need to, and I've often thought oh I've got a problem... and I know he's there if I need to talk to him. He's a lovely guy and I've seen him professionally and we go out at Christmas and what-have-you and always think oh there is that resource there. But I think it's the... just the general philosophy of the whole of the surgery, only one surgery bearing in mind I've got six to cover. Just that one where I can just go in to that surgery and just phew... and just feel part of being there, belonging, so...I don't feel that in any of the others...whereas this particular surgery I'm talking about is like family, my work family – I have my home family plus my work family' (participant 9 Community p. 19)

Only one respondent inferred that informal support might fall short of need. In the same way as rapport with patients facilitates trust and open dialogue with nurses, so to staff need to have a trusting rapport with colleagues if they are to be able to share their feelings in times of vulnerability. Respondent 1 described how she felt that staff changes over a period of time had in some way reduced the supportive ambience of her work environment:

'I think when I started here – you know, there's been quite a few staff changes – staff seemed to be aware of that (need

for support) *and a little bit more of a general sort of caring for each other attitude*' (participant 1 Hospice p.17)

6.6c Formal support for nurses

Formal support does have cost implications, not only in time, in taking staff out of clinical situations, but in remuneration for specialist support. One nurse had found a hospice forum in which staff explored actual case studies that involved challenging patient and staff issues particularly helpful in working through things that *'weighed heavily on her mind'*. Attendance was voluntary. At interview the respondent's account was very much a reflection on the loss of what had been helpful, which was further evidenced by her seeking to find out why these meetings had stopped:

'...it was sort of like they did a one-off group counselling session that was actually run by a counsellor and where you could go and just sort of say...you know, you could say what you found really hard...– and it was the psychotherapist who led that from outside the hospice, and it was absolutely...I thought it was really good, I hadn't been here long and I really had some... I was named nurse for this patient who sort of ... what is the right word... there were some really big issues there, and I really liked this patient and there was just so many things and it just weighed heavily on my mind...and as a nurse (I) could say 'oh I would like to do this on such-and-such patient' and I did that, and you know it was brilliant! ...you then presented your patient with the problems and there were...nurses and social worker, and the doctors used to come, and there used to be slightly better staff(ing) I think, and it was really encouraged, and the psychotherapist... anyway I did think beforehand that it wasn't going to do something but it really did, it just all ...it laid everything to rest. And that...stopped and I was told because of finances' (participant 1 Hospice p.17-18)

Education that facilitates understanding is another potential source of formally accessed support. Biographical details collected at the time of interview indicate that all respondents had accessed study focused on palliative care except participant 11 who was a community nurse and one of the youngest respondents (Appendix 8). Hospice and nursing home respondents had also participated in specific courses on loss and bereavement. Although a number of participants had achieved specialist graduate qualifications the majority of

courses attended were not accredited and had been provided by the hospice local to the research participants' work environment. This reflects the ethos of hospice in educating the wider professional workforce in the principles of end of life care.

Appreciation of funding for formal support was described by a respondent employed in the nursing home practice environment. She implied that training was a form of formal support and found any reasonable choice of further study was met with approval:

'I suppose training: it was my choice to do the palliative care course. And if I saw anything that was available...I would feel confident I could go and ask and they would fund it within reason.' (participant 5 Nursing Home p.18)

The most senior nurse among the participants valued formal support sourced from outside her own institution for particular issues. Although she appreciated informal day to day support from engagement with members of the hospice staff, she implied that there were particular issues at her level of working that were better discussed in clinical supervision sessions outside of her immediate environment:

'...I have a very good clinical supervisor so I will take some issues there' (participant 6 Hospice p.4)

The particular benefit of external supervision is described as giving her a different perspective. She was now in a nursing management role and was responsible for supporting her clinical managers and their teams. External supervision helped with the bigger picture and understanding individual response in that context:

'It's more about looking at the whole picture of why do you feel like that, why do you respond like that, why does that person respond like that, so it's changed as I've changed. My needs have changed, so if I had a supervisor here – well, it would be very difficult to find somebody to meet the needs that I have now. But, also... I mean that's like one aspect, but another aspect I find it going externally, just getting away from the building and the people and talking to somebody that doesn't have a palliative care background, doesn't even have a nursing background, I get whole

different perspectives on things.’ (participant 6 Hospice p.5-6)

In particular difficult situations, when additional support is needed for the clinical team she is unable to locate additional support for herself at the hospice because her peers manage non-clinical hospice services. It is at times such as these that she can opt for additional supervision for formal support:

‘I think the higher up you get probably in any environment but ...palliative care in particular...the less support you get because there’s nowhere to go...the colleagues that you’ve now got at that level come from different departments so won’t understand it and recognise it in the same way. So I think it does get harder...for that extra bit (of support)... maybe... that’s the sort of issue I would take to supervision and talk it through...’ (participant 6 Hospice p.11-12))

Only one participant referred to formal support that was obligatory. This form of routine, regulated supervision by a manager was not felt to be particularly helpful. Although the respondent did not explain why, her expression at the thought of these meetings certainly conveyed displeasure:

‘...we have to have supervision at least six times a year so the deputy manager will sit you down every couple of months and will give you supervision, its not very good quality’ (participant 3 Nursing Home p.22)

The need for staff to actively seek formal support was exemplified by a situation involving a mentally ill patient admitted to the hospice for a prolonged period. The mental health needs of the patient were difficult for nurses with little experience and no formal training in mental health care. The respondent explained how they needed formal support, and refers to the forms of support available to help them cope. She also outlines what it was they found particularly difficult to cope with:

‘We went through a very hard time during the time that he was here. We were supported. We had to seek support at various times from the family support team for ourselves, and we had debriefings, because again we are all individuals and our level of...our coping mechanisms are different, and we were all trying to cope with this one man who was very intelligent and he had been sort of institutionalised nearly all his life and he knew how to manipulate people to satisfy his own needs, his own care needs and that was extremely difficult for a lot of us,

particularly the younger ones, the manipulation. So we needed quite a bit of spiritual care during that time'
(participant 2 Hospice p.23)

None of the community team made any mention of formal support. Three had accessed courses on palliative care at the local hospice. Therefore, only participant 11 appeared to have been in receipt of no formal support at all, which is a potential source of concern as she also indicated that she tends to take her thoughts about what is 'hard' home rather than seek informal support with her community colleagues.

6.6d Summary; *belonging as the means of maintaining spiritual integrity*
'Right relationships' provide a spiritually supportive ambience in the workplace. Spiritually supportive work environments facilitate support for nurses in the provision of care that exceeds their boundaries of experience. Additional support for patients and their relatives was provided by a counsellor, chaplain, a volunteer from a local church, a community psychiatric nurse, a responsive general practitioner, MacMillan services and additional nursing services. Family relationships played a significant role in supporting patients, particularly where members of a patient's family helped them deal with unfinished business. A shared value system drives work ethos and understanding of what is meant by having done a good job and therefore it is not surprising that most participants chose to look to their immediate or wider team members for informal support in coping with the emotional challenge of recurrent exposure to situations of loss. Most participants had access to formal support, either through education, group or individual supervision.

6.7 Conclusion

Findings reflect the significance of the nurses' own spiritual development in relation to their aptitude to help patients utilise spirituality as a means of coping with loss.

Nurses' experiences of the dominant issues of loss differed dependent on their working environment, but regardless of whether loss was associated with dying, death or chronic illness there was evidence of agreement that loss was

not just about physical functioning but impacted social role, cognition and control. Sometimes an individual's cocktail of loss was particularly challenging and generated existential questioning.

Nurses' personal belief whether one of faith or philosophy, religious or non-religious, helped them make sense of situations of loss. In understanding individual belief as a resource and supporting patients in theirs, nurses encouraged coping in situations of spiritual need or spiritual distress.

Helping patients cope hinged on knowing something of them as an individual and therefore the nurses' ability to develop rapport within a trusting relationship was crucial. Spiritual assessment as an integral part of holistic appraisal of individual need was an on-going process and more about the 'how' rather than 'what' nurses did. Hence, the nurses' communication skills were significant in their aptitude to both identify patient's spiritual need and give spiritual care in facilitating coping.

Each nurse's story reflected a pattern of spiritual development. The youngest participants inevitably had less experience and appeared on the threshold of development. Others had described incidents that reflected their emerging development in understanding spiritual care and their role in that. The older and most experienced nurses had a story to tell of how they had arrived at their understanding of spirituality and for some, how their aptitude for spiritual care had been strengthened by the experience of significant personal loss. Findings reflect the importance of experience in developing the skills of sensing and intuiting patients' spiritual needs and effecting responses that promote coping.

In sharing themselves within therapeutic relationships with patients nurses also shared patients' experience of loss, albeit in a different way. The emotional impact of such loss was evident in responses that include reference to tears and needing to 'let off steam'. In order to cope nurses needed support within a therapeutic relationship themselves, one of shared understandings in which they could come to terms and make sense of their loss. Consequently,

coping was centred on the supportive relationship they had within their nursing teams.

The nurse's development of spirituality as a constituent part of being an individual, and its consequent impact on their aptitude for utilising spirituality as a resource to help patients cope with loss are discussed further in the next chapter in relation to available relevant research and published literature

Chapter 7

Discussion

7.1 Introduction

The study aimed to explore nurses' experience of utilising spirituality as a means of helping patients to cope with loss associated with terminal, or chronic disease, and specifically to address three objectives. These were firstly, to gain an understanding of nurses' perceptions of spirituality as an aspect of person centred care, secondly to explore the extent to which nurses facilitate spirituality as a resource for coping with loss, and lastly to explore how nurses use their personal resources when caring for patients and their significant others in situations of loss. The Heideggerian hermeneutic phenomenological approach that was chosen as methodology proved effective in producing data that addressed both the study's aim and objectives.

Study findings reflect the significance of the nurses' own spiritual development in relation to their aptitude to help patients utilise spirituality as a means of coping with loss.

- Their experiences of the dominant issues of loss differed dependent on their working environment. Coping with the emotional impact of issues of loss was centred on the supportive relationships they had within their nursing teams.
- Nurses' personal belief whether one of faith or philosophy, religious or non-religious, helped them make sense of situations of loss. In understanding individual belief as a resource and supporting patients in theirs, nurses encouraged coping in situations of spiritual need or spiritual distress.
- The nurses' ability to develop rapport within a trusting relationship was crucial, and therefore, the nurses' communication skills were significant in their aptitude to both identify patient's spiritual need and give spiritual care in facilitating coping.
- Each nurse's story reflected a pattern of spiritual development, as well as the importance of experience in developing the skills of sensing

and intuiting patients' spiritual needs, and effecting responses that promote coping.

This chapter draws on existing theoretical knowledge and concepts to further develop the discussion of study findings and critically evaluate methodology. The discussion starts with considering the impact of loss as a context of care, and includes issues that emerge from the super-ordinate themes 'loss as a spectrum' and 'belonging as the means of maintaining spiritual integrity in situations of loss.' Next, discussion concerning impact of process on proficiency in spiritual care builds on findings drawn from the super-ordinate themes 'belief as the pillar of spirituality,' 'being a "spiritual carer"', and 'becoming proficient in spiritual care'. This section of the discussion indicates what is novel about the study, in evidencing how participants grow in spiritual maturity, and how this growth contributes to their proficiency in spiritual care. The discussion concludes with a review of the effectiveness of methodology. Table 7.1 provides a more detailed indication of the structure of the discussion. Super-ordinate theme titles are colour coded as previously to promote clarity in explicitly linking the discussion with analysis and findings presented in chapters 5 and 6.

Table 7.1: Outline of the structure of the discussion

Impact of loss as a context of care				
7.2	Loss as a Spectrum	(a)	Difference in relation to practice context	(i) Dominant issues of loss (ii) Nursing team dynamics: Belonging as the means of maintaining spiritual integrity in situations of loss
		(b)	Similarities in relation to process of care	(i) Consequences of loss for patients (ii) Impact of loss on nurses
7.3	Impact of process of care on proficiency in spiritual care.			
7.4	Belief as the pillar of spirituality	(a)	The search for meaning	(i) Man's 'will to meaning' (ii) The impact of education on spirituality as meaning and 'relational consciousness' (iii) Constructing meanings and growth of the self
		(b)	Narrative as a tool for meaning making	
		(c)	Meaning made over time, 'retrospective reappraisal' and forgiveness	
		(d)	Congruence as a concept facilitating meaning	
		(e)	Hope and its contribution to finding meaning in situations of loss	
7.5	Being a "spiritual carer"	(a)	The nature of the nurse patient relationship	(i) The nurse as spectator (ii) The nurse as participator (iii) Being concerned (iv) The nurse presence (v) The language of companionship
		(b)	Means and style of communication	(i) Issues of style in communication (ii) Means of communication

Table 7.1: Outline of the structure of the discussion (continued)

7.6	Becoming proficient in spiritual care	(a) Possibilities in ‘becoming’ a person (b) Personhood and shared vulnerability (c) Personal growth in bereavement (d) Professional growth in experience (e) Professional maturity and spiritual care		
Reviewing the effectiveness of methodology				
7.7	Benefits and limitations	(a) Challenges of phenomenology as methodology (b) Rigour in determining how many interviews were enough (c) Trustworthiness as a means of determining qualitative validity (d) Transferability: a question of usefulness	(i) Accessing the ‘mental universe’ of another (ii) The nature and value of intuition (iii) The complexity of experience	

7.2 Loss as a spectrum: the impact of loss as a context of care

The impact of loss as a context of care is twofold in respect of both practice context and process of care. Practice context has determined the dominant issues of loss and the dynamics of the team to which nurses belong. Process of care was both related directly to patient need, and, almost circumstantially, has contributed to the spiritual development of the nurses themselves, the outcome of which impacts their proficiency in spiritual care.

7.2a Difference in relation to practice context

Given that the research sample included participants from three different practice contexts it is not surprising that some differences were identified.

7.2a(i) Practice context in relation to dominant issues of loss

The differences in dominant issues of loss between the working environments of research participants reflect the range of service provision for end of life care. Hospice nurses' focus was primarily on dying and death, community nurses' was supporting patients and relatives with losses related to relationship and associated activity, and, in the nursing home environment nurses supported their patients in their loss of 'home' or 'life'. These differences also illustrate the continuum of end of life care provision, from the supportive environment of a nursing home for those with progressive chronic illness that will render them in need of end of life care in due course, through support that enables those adjusting to losses in the throes of their end of life journey to remain in their own homes (including nursing homes), to intensive care for those patients admitted to hospice with challenging needs, half of whom are near death. Protocols for addressing care of the dying, adapted for each of these practice contexts, have been devised and disseminated nationally. These protocols include addressing patients and relatives spiritual issues. (Thomas, 2003; Ellershaw and Wilkinson, 2003).

Financial resources supporting choice in effecting spiritual care in the different practice environments also varied. Art and creative writing were accessible onsite at the hospice. Certainly, art is well established as a therapeutic tool that can gradually awaken, or illuminate, patient perceptions

in situations of loss (Stanworth, 2004; Adams, 2006). Similarly, the therapeutic benefits of writing are reported as a way of making sense of loss associated with dying (Bingley et al, 2006). In contrast, nurses employed in community and nursing home practice, primarily, relied on advocacy to uphold patient choice regarding decisions related to existential issues, which impacted their care. Some financial resources may have been wasted, for example, the ineffective use of clinical supervision in the nursing home, and some, reduced or redirected, for example, the cessation of interprofessional group supervision in the hospice.

7.2a(ii) Practice context and nursing team dynamics: belonging as the means of maintaining spiritual integrity in situations of loss,

Belonging to a nursing team is a primary source of support in end of life situations. Team dynamics are therefore particularly important when nurses are caring for patients and their significant others in situations that can be emotionally demanding (Field, 1989). Although participants' teams shared the goal of providing holistic care for patients nearing the end of their life, their team cultures differed across practice contexts in the style of support sourced within the teams.

Barnard et al's (2006) study of palliative nursing implied collegial working involved a shared responsibility, not only for patient care but in supporting one another. Hospice care is provided primarily for the terminally ill. The ratio of registered nurses to patient numbers is high due to the need for 'intensive care' for patients who are usually admitted for specialists to manage symptoms that have been too challenging for professionals to manage in other environments (Randall and Downie, 2006). Therefore, although situations that the participants faced were at times harrowing, they were never 'alone' in that there were always other registered members of the nursing team on shift and so collegial support was available.

In community care a shift in health policy due to 'sicker patients...living longer' (Thomas, 2003 p.29) has resulted in increasing numbers of patients, and the complexity of their needs associated with end of life care, contributing

to an increasing workload. Both patients with advanced chronic disease and terminal illness are cared for at home for longer, rather than being admitted for institutional care. In these circumstances the ratio of registered nurses to patients needs to be robust, but access to support in difficult circumstances is delayed or dependent on catching a colleague 'back at the office' due to logistics leaving the nurse 'alone' while traveling and visiting patients.

In the nursing home environment individuals are almost exclusively elderly and, on admission, may only need supportive care. However, over a period of time, the clients grow more dependent and ultimately require end of life care. In order to manage such a range of need and remain financially viable the ratio of registered nurses to clients in this environment was lower, with perhaps one registered nurse managing a team of care assistants on each 'floor' of the nursing home. Consequently, the culture of support within the team differed in the nursing home. It appeared to constitute a tripartite system. Participants, as registered nurses, were responsible for supporting support workers who worked on the floor that they were in charge of. Secondly, there was evidence that participants supported each other. However, this support was not necessarily immediately available, despite their working in an institutional environment. This was because the limited number and geographical spacing of registered nurses leaves them 'alone' in practice when facing difficult circumstances. Hence, support is delayed until they are able to ring a colleague at home or arrange to meet, perhaps for peer supervision. A third facet of support was from the manager outside the immediate nursing team, which included clinical supervision, although this was not considered beneficial. Nicklin's (1997) model outlines the three complementary, but often contradictory functions of supervision. Firstly, normative function is managerial and focused on delivery of efficient and effective care, secondly, formative function is educational and concerns skills maintenance and development, and thirdly, restorative function is supportive and addresses managing and minimising occupational stressors. The purpose of clinical supervision is to sustain the balance between these functions. If supervision was skewed and failed to address restorative functions adequately this may account for why it was not helpful.

7.2b Process of care

The 'process' of care constitutes those activities that go on within and between practitioners and patients (Donabedian, 1980). Although dominant issues of loss differed across practice context, the participants' accounts of the consequences of loss for patients, was not context specific. Similarly, difference was not an issue in regard of the impact of loss on nurses. Process of care was therefore, focused on helping patients with the consequences of their loss, and in nurses coping with the impact of recurrent involvement in situations of loss.

7.2b(i) Process of care in relation to consequences of loss for patients

Participants promoted patient coping by utilizing their experience and awareness of cultural difference to action or 'do' spiritual care in facilitating religious practice, promoting patient's choice through empowerment or advocacy, and accessing support for care that exceeded their professional boundaries. However, the primary means for participants to both determine need, and provide spiritual support for patients in situations of loss was in their ability to develop a rapport and trusting relationships with patients, and so, seated in their development of a particular style of 'being' caring. This affirms current knowledge of the importance of nurse-patient encounter as not merely one of 'dynamics', of 'doing', but also one of 'atmosphere', determined by the attitudes nurses have, and 'spirit', in the way they 'are' in caring (Muetzel, 1988). In addition, it affirms experience of caring as a contributory factor in developing the level of sensitivity required in determining when 'being with' a patient, rather than 'doing to', or, 'doing for' a patient, addresses spiritual need (Stoter, 1995)

7.2b(ii) Process of care in relation to the impact of loss on nurses

The impact of loss on participants was evident in their responses, and affirms current knowledge in relation to the emotional responses that such situations evoke (James, 1989), as well as the culture of stress and coping in end of life care contexts (McNamara et al, 1995). In getting to know their patients over a period of time the death of a patient was a situation of loss for the nurse as well as the family. Participants developed their own spiritual resources to cope

and in so doing promoted proficiency in spiritual care. Faith as a means of regulating distress, together with their personal philosophy, provided effective coping strategies that enabled repeated exposure to loss. Replenishment, sought outside the work environment reflected nurses' self awareness, in maintaining personal spiritual integrity.

7.3 The impact of process of care on nurses' proficiency in spiritual care

Spirituality is experiential in nature, and therefore an understanding of this concept tends to be 'caught' rather than taught (Bradshaw, 1997). An understanding of spirituality in health care contexts can be promoted in education forums by experiential methods of delivery, and can benefit nurses' development in relation to spiritual care (Greenstreet, 1996). However, it is in the practice environment that an interface with existential issues can really hone nurses' understanding of spirituality. Therefore, it is in the process of care, in the throes of those activities which go on between nurses and patients (Donabedian, 1980) that spiritual development is more likely to occur. Hence, it is in participant descriptions of the process of care that the means by which they gain proficiency in spiritual care is illuminated.

The super-ordinate themes belief as the pillar of spirituality, being a 'spiritual carer', and becoming proficient in spiritual care, particularly incorporate descriptions of process. The following enhanced discussion of these themed findings change our understanding of the nurse in relation to spiritual care in situations of recurrent loss, in that, how participants grow in spiritual maturity, and how this growth contributes to their proficiency in spiritual care becomes apparent. In this way what is novel in this study is made explicit.

7.4 Belief as the pillar of spirituality

Published literature already asserts the importance of nurses clarifying their own spiritual stance if they are to support patients asking 'ultimate' questions as they face real life and death issues of existence (e.g. Burnard, 1988; Cornette, 1997; Greenstreet, 2006d). This remains important because, in contemporary secular society's predominantly materialistic culture, there is little encouragement to do so (Jarvis, 1993). The void that has resulted from such a soulless culture is being increasingly recognised, and generating, what

a number of authors have suggested is a revolution in spirituality (Tacey, 2004; Heelas and Woodhead, 2005). Although, resultant change has tended to be emergent, rather than striking, for example, there is evidence of an increasing interest in complementary therapy given by '*alternative*' spiritual practitioners (Heelas, 2006 p9).

How an understanding of belief is achieved varies. In applying our consciousness to search for an understanding of how and why things happen, if we come to uphold a belief, even if there is no proof, then we are said to make an explicit profession of faith (Polanyi, 1946). If our search for the truth is more a matter of conceptual analysis, or thinking about thinking, then we are destined to arrive at a philosophical conclusion to our quest (Hankinson, 2005). Regardless, participants' responses demonstrate that belief has been a significant resource in their experience of loss, and has impacted their aptitude for spiritual care. Therefore, there is a future need to emphasise not merely an awareness of personal spirituality, but also encourage a more thorough understanding of belief imbued in practice as described by participants. Timmins (2013) shares this concern, in a self-reporting survey used to collect data based on nurses' views of spirituality, she found that much of nurses' ability to provide responsive spiritual care was based upon their own personal experience due to a the lack of specific education facilitating a broadening of perspective.

In their hermeneutic study that explored the meaning of spirituality and spiritual care McLeod and Wright, (2008) define belief as '*a persisting set of premises about what is taken to be true*' (p.121). In twelve therapeutic conversations with three families living with serious illness, they found that belief could facilitate health and healing if it helped family members find some meaning that they could live with, whereas meaninglessness created suffering. McLeod and Wright's, (2008) study, therefore, illustrates the role of belief in meaning making.

7.4a The search for meaning

Establishing belief is a complex process impacted by individual development and experience. The search to understand meaning of either, immediate circumstances, or the meaning of life itself, can be triggered in situations of significant loss.

The narratives of the spiritual journey given by several participants described how they have arrived at their current belief. Involved in religious communities in their childhood, religious belief had been external and needed to be 'learnt' by each child. Some spoke of their rejection of religion, and others sought their own interpretation of religious faith as they moved toward adolescence and early adulthood. This shared, similarity of pattern of development of belief, that involved challenging what they had been taught to believe, was not evident to participants themselves, nor was it recognized in patient assessment. There are a number of different perspectives on why the pattern of development of belief follows a similar pattern:

7.4a(i) *Man's 'will to meaning'*

Frankl (1984) believes that man's search, his '*will to meaning*' (p.121), is the primary motivation in life. Hence, the rejection of religion may reflect the intrinsic need for individual participants to search and discover for themselves how they are to make sense of existential questions, even if ultimately, they find their answers in the organised beliefs of the religious community they rejected. Regardless of initial outcome and ongoing discovery, the participants' search contributed to clarity of their personal spiritual stance. This clarity promotes nurses' spiritual integrity when caring for vulnerable and distressed patients (Cornette, 1997).

7.4a(ii) *The impact of education on spirituality as meaning and 'relational consciousness'*

Culliford (2011) suggests that the timing of a decline in religious or spiritual interest coincides with the contradictory educational influences of children's introduction to the traditions of science, often accompanied by religious scepticism. This is supported, at least in part, by Hay and Nye's (2006) study

which used a grounded theory approach to develop a theoretical interpretation of children's spirituality.

Permissions were gained from the head teachers and the parents of thirty eight children who attended primary school in two industrial cities in the English Midlands to participate in the study. Children were randomly selected (subject to the proviso that samples included an equal number of boys and girls), eighteen were six to seven years old and twenty were ten to eleven years old. Approximately three quarters of the children were classified as having no religious affiliation. Hay discusses at length the challenge of talking to children about spirituality. The outcome was that Nye spent time in the primary schools so that she became a familiar figure to the children. She also invited each child to tell her about their life and interests at the beginning of meetings in order to put the children at their ease before moving on to a focus on spirituality. This shift in conversation was triggered by the use of photographs chosen to generate awareness, value, or mystery sensing, for example, a photograph of a child gazing into a fire, or of a child staring at a dead pet. After listening to the child's reflections Nye encouraged the children to share any similar experiences of their own.

Nye conducted up to three meetings with each of the children and tape recorded these conversations which lasted about half an hour. In the analysis of this data the core of children's spirituality is described as '*relational consciousness*' (p.115). Excerpts of conversations illustrated that spirituality was experienced through a child's 'sense of' relationship with the natural world, to others, to God, with their own identity and their own mental life. Hay goes on to suggest that spirituality expressed as '*relational consciousness*' is an ever-present aspect of being human, a holistic 'sense', or 'direct knowledge of', separate from and prior to intellectual 'knowledge about' phenomena, in much the same way as Heidegger (1962) proposed that we are primordially immersed in 'Being' (see 7.4a: 175). Hay considers the primal nature of '*relational consciousness*', accounts for why it can be seen particularly clearly in children. In pre-dating intellectual analysis it constitutes an awareness of our link with the seamless robe of reality, and therefore our

awareness that '*damage to any part of reality is implicitly perceived as damage to the fabric of which one is a part*' (p.135). Hence, self-sacrificing behaviour for others is seen as a function of spiritual awareness. This concept is not dissimilar to nurses partaking in the sharing of self in professional contexts, described by Campbell (1984) as 'moderated love', and by Bradshaw (1994) as covenantal care, and so, the participants who described experiences that illustrated their ability to practice in this way appear to have sustained something of their '*relational consciousness*'. However, Hay's concern, regardless of whether individual convictions are religious or secular, is that, our society's culture of individualism, promotes self-interest, which undermines human '*relational consciousness*' and so 'blots out' the holistic nature of spiritual awareness. Similarly, contractual care may 'blot out' spiritual awareness, in much the way participants described colleagues who were focused on task efficiency rather than establishing patient rapport.

7.4a(iii) *Constructing meanings and growth of the self*

Critical distancing and re-approaching religion is attributed by Kezdy et al (2011) to a change in attitude to religiosity. In their review of literature in preparation for a cross-sectional survey investigating religious doubt and mental health of Hungarian students, aged fifteen to twenty five, they described two dimensions of approaches to religion. The first of these is by the acceptance or rejection of a transcendent reality, the second is in the way religion is approached, as either literal or symbolic. A literal approach reflected a preference for clarity rather than ambiguity and the assumption that there is only one right answer for each problem. A symbolic approach, on the other hand, related to different cognitive variables, such as, open-mindedness and tolerance of ambiguity. Kezdy et al (2011) suggest these approaches to religion are reflected in Fowler's (1981) theoretical model of faith which draws on cognitive (Piaget, 1967), moral, (Kohlberg, 1974) and personality (Erikson, 1963) staged models of development. He describes the development of faith across the lifespan as having six stages, with few people reaching the final stage. Fowler's second stage of faith development is one that spans school years in which beliefs are expressed as literal interpretations. The stimulus to move on to the third stage, associated with adolescence, is the

occurrence of contradictions in these literal interpretations that require reflection on meanings. Such reflection demonstrates the changes in the complexity of thinking in adolescence that is necessary for symbolic interpretation described by Kezdy et al (2011). Fowler's further stages of faith development reflect an increasing relevance of an ability to tolerate uncertainties and accommodate paradox as an aspect of faith in adulthood. He has more recently explained that the structural aspects that constitute the matrix of faith *'is a... (story) of the self through time, as constructing meanings and being constructed, in a matrix of relationships and meanings that faith involves'* (Fowler, 2001 p.164). This growth of self reflects a spiritual maturity which in nurses promotes proficiency in spiritual care. This growth is ongoing and evident in the different stages of spiritual maturity reflected in participant stories.

7.4b Narrative as a tool for meaning making

Participant recognition of repetition of illness narratives by patients as a route to healing, unfolding awareness of achievement or insight by participants in the throes of interview, exemplify ways in which narrative works in relation to meaning making.

This process of meaning making is described by Carrithers (1992), an anthropologist, as narrative thought. He explains that narrative thought simultaneously involves action, for example, the situation I find myself in, and consciousness, such as the way I feel and what I know, or do not know, about that. It involves not only our knowledge and awareness of our immediate relation with another person, but also, the many human interactions we have had over a period of considerable time. In this way it allows us to understand complex action and to act appropriately. Hence, narrative thought is more than a means of telling stories as it also provides a way of understanding involved, intricate situations and attitudes. In this way, narrative provides a potential tool for nurses and patients, a spiritual resource, in that it facilitates making sense of situations of loss

7.4c Meaning made over time, ‘retrospective reappraisal’ and forgiveness

O’Connor (2002) reviewed available research, theoretical and empirical evidence on adjustment to negative life events. She explains that in order to find meaning in an event we explore the significance of the event in our lives overall. Meaning can be made over time by ‘retrospective reappraisal’ (Bonanno and Kaltman, 1999). Social sharing of feelings and reactions in conversation with supportive others has been found to be positively correlated with the emotional disruptiveness of the event (Rime et al 1991).

O’Connor (2002) goes on to propose a meaning-making model that could explain adjustment to loss. Meaning making is considered as a marriage of emotion and cognition, with meaning described as an important crossroads that allows us to move from negative emotion, due for example to loss, through a cognitive understanding of the event, to positive emotion. In this way the event does not merely have negative repercussions, but positive ones as well, such as the positive sense of achievement by participants in getting what dying patients want right, despite the loss of the patient through death.

This shift from a negative to positive emotion through cognitive reappraisal of the situation is similar to the concept of forgiveness, in which a past event, which cannot be altered, can be seen in a fresh light (Saunders, 1995; Stanworth, 2002; McCullough et al, 2006). The capacity to forgive oneself, to live with one’s flaws (Myco, 1985), is as important a spiritual need as forgiving another. Formally promoting an understanding of the concepts of forgiveness and retrospective reappraisal would contribute to proficiency in spiritual care in that they would raise nurses’ sensitivity to issues of guilt as a source of spiritual distress, such as those identified by participants who sensed issues of distress related to patients’ estranged relationships or personal history. Such understanding is invaluable in that it promotes optimism in offering potential ways of helping patients in distress.

7.4d Congruence as a concept facilitating meaning

Western culture predominantly values control, and as science and technology have moved the capabilities of medicine forward, this has driven an

expectation of people living to adulthood and beyond to an increasingly old age. It is therefore not surprising that participants found it difficult to deal with young, untimely deaths. Friedemann et al (2002) advocate a more congruent philosophy of health in which human control is balanced with spirituality as an alternative means of coping. Certainly some nurses made sense of tragedy by transcending the immediate circumstances of events and situating them in what Friedemann refers to as the natural order of events. This ability to transcend difficult circumstances exemplifies the development of spiritual maturity.

7.4e Hope and its contribution to finding meaning in situations of loss

Dufault and Martocchio (1985) describe hope as constituting two different spheres, generalised hope, which provides a sense of something beneficial to come, and particularised hope, focused on a particular goal in expectation of improvement. Data collected by participant observation, over a period of two years, of thirty five elderly people (over sixty five years of age) with cancer, was analysed. Results were confirmed by analysis of further data from forty seven terminally ill patients (fourteen years and older) with varied diagnoses, again collected over a two year period. Although this study was carried out some time ago, and is not generalisable due to the nature and size of samples, its' value is acknowledged in more recent research (e.g. Nekolaichuk et al, 1999). Generalised hope was found to protect '*against despair when a person is deprived of particular hopes*' (Dufault and Martocchio, 1985 p.380) and therefore is very relevant to end of life care contexts. It is rather nebulous in that it provides a positive glow (rather than a particular hope) that drives motivation to carry on, to persevere. Hence, generalised hope provides a way of living 'in hope'.

Participants' sense of living 'in hope' seemed to be driven by the integration of hospice philosophy in their end of life care practice. All but one participant had undertaken post registration study to enhance their understanding of hospice philosophy (Appendix 8) Focused on improving quality of care and holistic in nature, hospice philosophy incorporates the physical, psychological, social and spiritual needs of individual patients (Sepulveda et al, 2002). The

positive focus of care on the facilitation of ‘living’ until the event of death can generate generalised hope. This is exemplified in research by Webster and Kristjanson (2002) in which descriptions given by staff with long term experience of caring for the terminally ill implied a sense of “vitality” (p.15). Care of the terminally ill was described as “*a way of living*” (p.15). Similarly, in Barnard et al’s (2006) phenomenological study of palliative nursing, participants described how encounters with life-limiting illness increased their appreciation of valuing each day, the ‘*everydayness of being a person*’ (p.10).

7.5 Being a “spiritual carer”

Persons exist essentially in relationship with others (Habgood, 1998; Jewell, 2011). Philosophers have proposed a number of ways in which the idea of the ‘Other’ is integral to our self consciousness. Their thoughts provide a useful means of framing discussion concerning participants’ experience of relationships with their patients as a conduit of spiritual care and coping. In some ways, the nurse appears to act as a chameleon in becoming the sort of nurse the patient requires at any one time (Aranda and Street, 1999).

7.5a The nature of the nurse patient relationship

7.5a(i) The nurse as spectator

Sartre (1969) describes the self as a subject perceiving the ‘Other’ as an object. In some instances participants knowingly used this stance to distance themselves from patient situations. They exemplified Sartre’s claim that the very presence of the ‘Other’ puts us in a position of passing judgement on ourselves as an object. Their judgement of self was usually altruistic in that its intent was that of positive benefit. Justification for viewing the patient objectively was evident, to avoid contaminating their understanding of the patient’s spiritual needs with their own beliefs. Another use of this strategy was as a protective ploy in setting boundaries to maintain their own spiritual integrity. However, there is danger in perceiving a person as the ‘Other’, and this was exemplified by a participant who appeared to lack compassion in judging a particular patient, in attributing blame.

7.5a(ii)The nurse as participator

Heideggerian philosophy rejects the idea of the conscious self as ‘outside’ the world that this self or subject observes. Instead, he describes human beings as being in the world, not spectators, but interactive with others who are in the world too (Mitchell, 2006). Therefore, understanding a person needs to include an awareness of the person’s world (Walters, 1995). Participant strategies of assessment largely reflected their commitment to the development of a rapport and hence interaction with patients. Consequently, the nurses’ role could be described as one of participator, involving both an interactive relationship, and a focus on the individual patient’s situation.

7.5a(iii) Being concerned

The Heideggerian use of the term ‘care’ or ‘being concerned’ is part of our being and is expressed in the many ways we relate to things in the world (Crotty, 1996). The relationship a person has with *others* in the world is described by Heidegger as ‘solicitude’. If we do not ‘matter’ to one another, and do not trouble to acknowledge others, then we exhibit an inauthentic solicitude. If we show each other consideration and forbearance then we are said to exhibit authentic solicitude (Mitchell, 2006). Participants provision of spiritual care largely affirmed the authentic nature of their solicitude, for example, in their holistic approach to ‘being’ with patients (Carson, 1989; Davidhizar, 2000; Speck et al, 2004).

7.5a(iv)The nurse presence

The benefit of the concept of nurse ‘presence’ is conveyed by reference to Buber’s (1958) philosophy, in which he describes how the person, the ‘I’, emerges only through encountering others, and that the nature of ‘I’ depends on the quality of the relationship with the ‘Other’. He suggests that, when I enter a mutually affirming relationship with the ‘Other’, the relationship is both one of choosing and being chosen. The meeting of I and Other (I-Thou) is filled with the present for the duration of the encounter. Spiritual care, in this sense, lies in what happens between two persons, the, I-Thou relationship involving the human response to the presence of the ‘Other’ (Baldwin 2011). Stern (2013) calls this response a strong form of empathy that allows dialogue between two persons, even if they hold profoundly different views. In this

way the concept of 'presence' is very similar to that of authentic solicitude, but differs in that it is specific to a particular relationship, for example, overall participants accounts of experience reflect their belief and commitment to holistic philosophy in their approach to end of life care patients, in that they 'matter', as stated above, their solicitude was authentic, however, the descriptions of a 'deeper' connection between a particular nurse and patient was not driven by belief but a more intuitive reciprocity, of 'choosing and being chosen', a meeting of souls. This 'presence', that Carson (1989) describes as touching the patient's spirit in much the same way '*as a cool hand might soothe a fevered brow*' (p.165) is evidence of proficiency in spiritual care.

7.5a(v)The language of companionship

Gilbert (2011), like Campbell (1984), uses the term love as the means for professionals to address the innate spirituality of those in their care. In 'unpacking' this term Campbell (1984) compares 'moderated' love to companionship, whereas Gilbert (2011) refers to the languages of love in spiritual care. However, these perspectives conflate, the 'languages' of love are sourced in a relationship of companionship. These 'languages' are methods of using words, time, touch, and acts of service in particular ways as spiritual care. Some participants were explicit in describing their experiences and expressing their awareness of the significance of 'language' in this sense, in that, it is 'the way' that nursing tasks are completed that addressed patient spirituality, and 'how' words were used for questioning to trigger conversation with patients, as well the importance of making time to 'actively' listen to a patient that enabled healing. Others were less eloquent in their awareness but modeled their use of languages of love in describing their experiences. In this way participants implied difference in spiritual maturity.

7.5b Means and style of communication

7.5b(i) Issues of style in communication

Spiritual care in end of life contexts necessitates nurses 'staying with' those who are suffering and so risks involvement. Morse et al (1992) used autobiographical and biographical accounts of caregiver and patient interaction from '*lay literature*' (p.810) as sources of rich description of

human responses to suffering in the clinical setting. They used this material to illustrate their model of communication that describes nurses' responses to patients who are suffering. They differentiate between nurses' therapeutic communication as a '*connected response*' (p.811) to empathetic insight triggered by suffering and the alternative distancing strategies, the use of false reassurance to remain detached, and the pseudo engagement of a learned professional response as a means of nurses protecting themselves from suffering. Morse et al (1992) suggest that empathetic insight into suffering predates professional learning, and in this way, therapeutic communication as a '*connected response*' may be linked to '*relational consciousness*' described above (7.3a(i)II)

Participant accounts provide numerous examples of engagement with suffering through 'connected' responses, together with evidence that, sharing of self in this way is emotionally demanding. However, some staff are described as focused on efficiency and task, and support workers as tending to consider their role as one of tasks to complete rather having a more vocational view of caring. These examples demonstrate contractual care that fails to attempt a '*connected response*'. These shortfalls in style of communication were considered remedial through education. However, if the root of connected communication is seated in empathetic insight into suffering that predates professional learning, educational focus will need to be experiential, in order to open up the possibility of rediscovery. Culliford (2011), for example, describes the experiential activities of medical students learning to take a spiritual history as a means of improving listening and offering what he calls 'deep presence'. The process was one of conversation while 'watching' people for visual clues as well as setting the emotional tone of information. Students found a gentle unhurried approach best. This style of approach is also thought to have a beneficial therapeutic effect, a possible '*reciprocal empathy, the patient feeling directly the warmth and positivity emanating from the physician*' (p.240). Culliford (2011) advocates the potential benefit of all health and social care professionals engaging with patients in this way.

7.5b(ii) Means of communication

Communication is a key element of our 'Being' and being spiritual in our care of others. Heidegger (1967) describes 'Being' as the quiet power of the possible in that it presides over thinking and, therefore, over the essence of humanity. In thinking 'Being' comes to language and hence is both manifested and maintained in language through speech. However, the flexibility and the multidimensionality peculiar to thinking are difficult to maintain as language complies to 'expedient' communication within a public realm where what is considered intelligible and unintelligible is already decided. Only in alternative forms of communication, such as, poetic creation or metaphor, can spoken language mimic thinking in being liberated from grammar.

Metaphor conveys a 'sense of' rather than direct meaning. It does this by comparing the unfamiliar with the familiar but also seeks to establish familiarity between speaker and listener. In expressing what is difficult to put into words the speaker uses metaphor as an invitation for the hearer to make a special effort to accept and so share 'a sense of' what the speaker is trying to convey (Madsen, 2005). On occasion some participants used metaphor to convey meaning. In this way they illuminated their potential ability to understand metaphor, to listen for multidimensional thought, and associated sensitivity, to the essence of meaning being conveyed when patients find conventional grammar falls short in the expression of spiritual matters. Understanding the use of metaphor and sensitivity to others' use of metaphor is a valuable asset in spiritual care.

7.6 Becoming proficient in spiritual care

Every person is considered to have a spiritual dimension, albeit not necessarily one that they have developed, or are able to recognise (Jewell, 2011). Spirituality is not an intellectual exercise but a lived experience (Wright, 2002), and as such, its development contributes to a person's awareness, or consciousness, of spiritual matters. Hence, nurses who 'become' more spiritually mature are more likely to be able to help patients engage with spirituality as a resource.

7.6a Possibilities in ‘becoming’ a person

Heidegger begins his analysis of humanity, of people’s everyday existence, from the premise ‘we are what we do’ (Crotty, 1996). ‘Dasein’ is a term Heidegger uses to describe a way of ‘Being’ in the world, not as ‘a thing’, subject or object, but more of an ‘*active self-creating and self-maintaining doing*’ (Mitchell, 2006 p.105). The dynamic represented by the term ‘Dasein’ is therefore comparable to the notion of ‘becoming’ a person. The range of possibilities for Dasein, for ‘becoming’, in all dimensions of life, is in the public domain, in ‘everydayness’. However, the public domain described by Heidegger as the impersonal ‘they’ levels off genuine possibilities, and so, individuals distance themselves from each other and from themselves (Heidegger, 1967). In this way Dasein, as a mode of ‘Being’ in the world is absorbed and held in subservience to everyday “chatter” (p.222) which dissolves any real life and death issues of existence.

A potential coping strategy used in situations of loss is the use of everyday “chatter” to escape the real life and death issues that these circumstances tend to throw up. Support workers were seen to use “chatter” to distract themselves, or the patient, from an issue that is a matter of concern. In using false reassurance they remain detached from the patients’ suffering, but, in doing so, may appear callous (Morse et al, 1992). Support workers need to grow and ‘become’ more spiritually mature in their delivery of care was addressed by establishing a reflection group in which they were encouraged to share experiences. This group not only provided the opportunity to consider the development of more therapeutic communication skills, but also provided an opportunity to tease out existential issues that are the domain of Dasein, of a return to self, to ‘Being’ (rather than busy everydayness) as important in understanding the world. This reflection group evidences a clinically based means of ‘how’ to raise spiritual awareness and promote competence in spiritual care.

If we ignore ‘Being’ we risk what Heidegger (1967) describes as human ‘*homelessness*’ in which ‘*the essence of man stumbles aimlessly about*’ as man ‘*observes and handles*’ only other beings and remains oblivious to the truth of

self, in just 'Being' (p.242). Yet Daesin is already 'there' but through intellectual arrogance we forget this. Individuals can still experience nearness to Dasein, to 'Being', in what Heidegger (1967) refers to as '*the clearing*'. This experience of 'Being', is described as '*homecoming*' or '*homeland*' (p.241). A number of participants' responses reflected what might be construed as their ability to spend time in '*the clearing*' and experience '*homecoming*', through activities that replenished self and solitary activities to reconnect with self. In this way they demonstrated spiritual maturity.

Sheldon (1997) explains that there are limits to working in end of life care contexts, boundaries that need to be adhered to if the professional is to preserve their own integrity, and in this way not suffer human '*homelessness*'. Maintaining a balance between their work and home life, was one way in which participants maintained boundaries. Humour was also a means they used of maintaining perspective and so preserving integrity in end of life care practice. Culliford (2011) describes spiritual practice as any regular activity that promotes spiritual development and includes humour as a means of connecting with joy in his repertoire of spiritual practices. He cites research that supports the physical, psychological and social benefits of humour and explains that good humour is not all about laughter but radiates from the spiritually mature.

7.6b Personhood and shared vulnerability

Situations of patient loss rendered some participants more aware of their own vulnerability as persons. When we are in the presence of another, the call to respond to the other is what Levinas (1989) terms 'the Face' (p.83) It is in responding to 'the Face' that we become human (Baldwin, 2011). However:

'Prior to any particular expression and beneath all particular expressions, which cover over and protect with immediately adopted face or countenance, there is a nakedness and destitution of the expression as such, that is to say extreme exposure, defencelessness, vulnerability itself' (Levinas, 1989 p.83)

Hence, beneath all expressions adopted by 'the Face' is vulnerability, a steadfast exposure to invisible death in that mortality lies in the 'Other'. In looking into the Face we grow, become more aware of humanity and hence know ourselves to be mutually vulnerable. This vulnerability was evident in participant descriptions of practice experience that included a raised awareness of their own mortality. It also triggered a comparison of the patient's family's situation and their own or imagining themselves in the patient's situation. Recognition of vulnerability potentially challenges a person's ability to stay in situations of loss (Sheldon, 1997). Owning the need for support, rather than expecting 'stoically' to keep such fear to oneself, is the better (Vachon, 1988), and spiritually mature response to maintaining professional and personal integrity in situations of emotional duress. Such maturity was inferred in the variety of ways participants' accessed support, and made explicit in relation to support for support workers who were less familiar with death, and so potentially more vulnerable.

7.6c Personal growth in bereavement

Stories of life changing personal loss and negative experience were found to contribute to a positive development of self and a better understanding of patient and family situations in practice by some participants. These experiences reflect a growth in resilience following biographical disruption (Bury, 2001), as time effects a shift from emotional upheaval to coping.

In Folkman's (1997) longitudinal study of care-giving partners of men with AIDS she found the common theme associated with positive psychological states for those coping with severe stress was searching for and finding positive meaning in the event. Meaning is created by finding a redeeming value in significant loss. Participants found meaning in organ donation, national advocacy for others impacted by suicide, and the discovery of a new clarity, a new depth of understanding of grief. Lloyd (2011) supports these participants' claim to be in a better place in empathising with patients and relatives in end of life care contexts, because, resilient professionals are more likely to promote resilience in others by being able to use active listening

skills and make *‘contact with patients in the darkness of their situation and provide an anchor from which they can bounce back-generate resilience’* (p.147).

7.6d Professional growth in experience

The ability to persevere in the face of recurrent situations of loss was thought by a participant to be due to the development of life skills, sourced from the experience of encounter rather than taught. This view is supported in published literature. Dirkx et al (2006), for example, explains that transformative, deep learning challenges existing taken for granted assumptions and integrates our experiences of the outer world with the experience of our inner worlds. In this way significantly novel dilemmas, through critical reflection effect learning by changing meaning and perspective (Mezirow, 1997)

Nursing requires a particular mode of knowing, one that is sensitive to situations and the appropriate response (McLeod and Wright, 2008). This mode of knowing or ‘tact’ is tacit in that it is not drawn from principles but from practical knowledge (Benner, 1994). In this way experience also accounts for participants’ ability to sense a patient’s need without understanding why. Professionals experienced at being open in the presence of a patient learn to feel their feelings, to trust intuitive thinking that takes place below awareness, a form of non-discursive thought that occurs as the conscious mind processes the experience (Cassell, 1999).

7.6e Professional maturity and spiritual care

Finfgeld-Connett’s (2008) findings, following a meta-synthesis of 49 qualitative reports and 6 conceptual analyses of caring, describe the learned ability to cope with psychic and physical challenges in situations of caring as professional maturity. Such maturity reflects an ability by nurses to become deeply involved in caring for patients without succumbing to over emotional forms of helping. They also develop the means of protecting themselves and maintaining a healthy ability to replenish, or, reconnect with self.

In various ways, and at different levels, participants exhibited professional maturity in their ability to ‘get to know’ their patients, and ‘to stay’ in working environments that were repeatedly emotionally challenging due to patients’ loss, and loss of patients. Contributory factors that enabled them to do this included an ability to recognise their own vulnerability and seek support, engaging in activities chosen for replenishment, and solitary activity or ‘time out’ to just be themselves. In this way they safeguarded their spiritual integrity, a crucial element in the development of proficiency in spiritual care.

7.7 Reviewing the effectiveness of methodology; benefits and limitations

There are challenges that need to be acknowledged, however overall the choice of methodology has been effective in fulfilling the aim and objectives of this study. A particular strength of using an Heideggerian phenomenological approach is in the unfolding of what were earlier living encounters for the research participants. The methodology’s concern with ontology, with ‘Being’ is considered by Hofstadter (1988) as both scientific and disciplined:

‘...ontology as a scientific discipline is...nothing but the unfolding...in conceptual form...of what earlier was grasped only in the immediateness of the living encounter’ (p.xxiii)

Similarly beneficial is the integration of hermeneutics in Heideggerian phenomenology. This provides the means of interpreting participants’ understanding of phenomena involved in their encounters, captured as ‘texts’ of lived experience in interview transcripts

7.7a Challenges of phenomenology as methodology

7.7a(i) Accessing the ‘mental universe’ of another

Hermeneutic analysis is not focused on the mind of research participants but on attempting to understand the meanings of their accounts of experience recorded in interview transcripts. To compound this challenge, experience itself is not a perception of something outside a person but active refinement of expectations, nor is it a singular fragment of a subjective situation but is overall ‘global’ creating intention and meaning and connected with the whole life of that person (Gadamer, 1989; Alvesson and Skoldberg, 2008). Hence, key to assimilating the ‘*mental universe*’ (p.54) of another is intuition.

7.7a(ii) The nature and value of intuition

The intuitive grasp of practice situations was recognized by Benner(1984) in her descriptive research that identified five levels of competency dependent on a nurse's level of skill acquisition; novice, advanced beginner, competent, proficient and expert. Intuition was found to rely on perceptual ability based on prior experience. Hence, the novice's initiation into practice is guided by explicit rules, codes and formal procedures, but over time experience enables the practitioner to view situations holistically, and so, much of the nurse's knowledge is embedded in practice (Meerabeau, 1992). Again, in a phenomenological study of quality of life, Benner (1991) explains further that the differential attention paid to aspects of a situation cannot be reduced to mental representations, to an array of patterns with each pattern signifying a different meaning, but is more a case of ;

'...the experienced person who without knowing the particulars or the reasons, attends to subtle differences in patterns and subtle differences in relative importance of presenting issues' (p.7)

Although, intuitive judgement is contested by some as unscientific and lacking in evidence base, such as a critique by English (1993), McKinnon (2005) refers to scientific argument and more recent neuro-scientific research findings to support its credence in practice. As neural networks develop with experience, conscious rule-following behaviour is rendered redundant, the speed and sophistication of responses increase and associated areas of knowledge and experience result in the formation of pattern response matrices that serve intuitive cognition (Smolensky, 1988). The relationship between cognition and emotion is purported to be crucial in intuitive thought, driven by a 'sense of' or 'hunch' (McKinnon, 2005). This is supported in findings by Damasio et al (1996) and Damasio (2000) which highlight the role of the amygdaloid nucleus, situated in the medial lobe of the brain, as storing context related information on emotion relayed by the thalamus. In this way, the amygdala is able to indirectly retrigger emotion-associated behavioural

responses to external stimuli that have been experienced in the past (Roberts et al, 1998). This arousal influences higher cognitive centres and is thought to produce optimum performance. The value of intuition is therefore, linked to the argument that feelings are powerful catalysts for reasoned activity. Hence, as a nurse researcher, the use of intuitive judgement in interpretation of phenomenological data relating to nursing practice seems very natural. This, together with a broad knowledge of the subject of study, potentiated my ability to interpret the research participants' interview texts.

7.7a(iii) The complexity of experience

Reed (1994) describes the three different elements of Heidegger's concept of Dasein, the situation of 'being-in-the-world'. The first of these is attunement, or mood, which determines if things matter. The second is articulation or discourse by which things are related to their function, for example, Reed (1994) refers to the 'hammering' of a hammer. Comparably, 'nursing', as a global term for the many complexities that constitute the function of the nurse could be considered in terms of discourse. This is illustrated above in Morse et al's (1992) consideration of nurses' responses to patients who are suffering. Communication is a significant constituent of 'nursing', however, the way in which nurses related to this function reflected their different situations of 'being-in the- world', in how they related to nursing, some using forms of therapeutic 'connected' communication and others preferring to use distancing strategies. The third element of Dasein is managing the world to achieve a goal, or the 'for-the-sake-of' activities. These three elements represent the way in which we engage with experience, the past, present and future of 'Being'. Hence, attunement represents the way in which we meet experience, articulation the way we have experience, and the goals are our potential, which is where experience leads us (p337-8).

A potential hazard of phenomenological methodology is to inadvertently simplify the complexity of experience by focusing primarily on the immediate lived experience of the participant, to elicit articulation, the way they had an experience, at the expense of a more complex account (Reed, 1994). Fortunately, the conversational nature of interviews conducted for this study

facilitated the elicitation of data in the form of accounts of past experiences as well as present practice and potential future goals. Some participant stories of personal experience, for example, illustrate attunement and how their past contributes to 'Being' in current practice (e.g. participant 2, 6.5d).

7.7b Rigour in determining how many interviews were enough

The in-depth nature of interviewing to elicit the deeply embedded meanings in everyday life and language of the individual participant, to make the 'unspoken visible and audible', requires small sample sizes (Higginbottom, 2005). Sampling was purposive in selecting experienced nurses working with those who are dying in specific care contexts. There are a number of ways of considering how many qualitative interviews is enough (Bryman 2012). An example is the possible issue of a minimum requirement for sample size in qualitative studies. However, Bryman (2012) acknowledges the vast variation in suggested optimum numbers in published work and consequently that actual sample size in qualitative studies varied enormously. Charmaz (2012) uses Guest et al's (2006) work to illustrate a point that supports the adequacy of a sample size of twelve nurses. They conducted an experiment to address the question of how many interviews are needed in qualitative research by using their codebooks from an earlier qualitative interview study. They found that twelve interviews sufficed for most researchers who aim to discern themes concerning common views and experiences among a relatively homogenous group. The style or theoretical underpinnings of a study is another factor that determines sample size. In this Heideggerian hermeneutic phenomenological study, data comprised transcripts of conversations shared by participants in semi-structured interviews. It is not necessary to generate large volumes of this style of data, because the style of detailed analysis occurs alongside data collection, and in so doing determines sufficiency of overall transcript text, and therefore, the point of cessation of sampling (Benner, 1994). The heterogeneity of a population is a further factor that may contribute to sample. Although homogenous in relation to professional group the sample reflected some heterogeneity in practice context. The sample of twelve nurses in this study was inclusive in relation to its sub-group variability. Another consideration of sample size is the breadth and scope of

the research question. A study with a particularly focused nature, such as, this study's focus on spirituality as a resource in coping with loss, is one that Bryman (2012) implies may support a small sample size.

7.7c Trustworthiness as a means of determining qualitative validity

Maggs-Rapport (2000) describes the issue of validity in qualitative research as involving both 'trustworthiness', in relation to it being 'right', and as a matter of persuading others that the study findings are worthy of notice, that they are useful. However, there is no certain rule in evidencing validity. This is reflected in the lack of consensus of terminology describing the qualitative research equivalent to what is conventionally referred to as reliability and validity in quantitative research, for example, Kahn (2000a) refers to 'reducing bias', Tuckett (2005) to 'rigour', le May and Holmes (2012) to 'credibility' and Morse et al (2002) suggest that the terms reliability and validity remain pertinent and should continue to be used in qualitative research.

In accounting for the trustworthiness of the findings of this research it is important to clarify what it is that I am claiming to be 'right' and, therefore, what is the 'truth'. Truth in this sense does not constitute reality as either subjective, in our heads, or objective, 'out there', but that reality both involves the researcher subjectively in the research and objectively as apart from the subject being researched, in this case the lived experience of the participants. In this way, valid knowledge, or validity of meaning, understanding and interpretation of phenomena, is a matter of relationship (Maggs-Rapport, 2000). Hence, as the researcher, 'my' engagement in interpretation of texts recording 'participant' experience creates an understanding of meaning reflected in my written account of analysis.

There are various accounts of the ways in which trustworthiness can be evidenced. Morse et al (2002) believe that there has been a subtle shift from concerns of validity to criteria and standards for evaluation of completed qualitative research. The use of critical appraisal tools, for example, those created by Sandelowski and Barosso (2002) and the Critical Appraisal Skills

Programme (2006), guide the assessment of rigour, credibility and relevance of qualitative studies. However, standards for evaluation of completed studies do not in themselves ensure rigour, relevance and usefulness. Also, validity does not rely on procedures external to the research but on strategies built into the actual research process itself (Morse et al, 2002). Therefore, it is through my use of research strategies, for example, being transparent in giving account of experience that impacts my perception in my fore-structure of understanding of the phenomena studied, that I am able to evidence the trustworthiness of this study. Further examples include a coherent rationale for methodology, transparency of method strengthened by including accounts from my research journal, audiotape recording of interviews to ensure dependability of data collection (Perakyla, 1997) and auditing of the independently transcribed transcripts against original audiotapes (Tuckett, 2005). Journal accounts reflecting each stage of the research process provide evidence of my self-conscious awareness of participation in both the data collection and its writing up as an interpretation of meaning (Kahn, 2000). Hence, my reflective journal enabled monitoring of 'what is going on' in methods (Koch and Harrington, 1998).

7.7d Transferability: a question of usefulness

Phenomenological philosophy focuses on the lived experience of the individual and therefore, as a research methodology, cannot produce results that are generalisable to a wider population. However, Higginbottom (2005) suggests that for some qualitative studies, 'typicality' may be considered in relation to the extension, or application, of findings to other populations similar to the study sample. The question that this poses is how 'typical' are the nurses who participated in this study, in relation to the overall population of experienced nurses whose practice includes end of life care in hospice, community, and nursing home settings? Ultimately, as there are no foolproof ways of accessing the essential nature of experience, it is for individual nurses practicing in end of life care environments to judge if this study is of interest to their practice development.

Heideggerian philosophy uses language in ways that are not commonly understood and, if used to couch research questions and report outcomes may limit the value and accessibility of findings (Clarke, 2004). Here, however, examples of nurses' responses to an invitation to share their experience of spirituality and loss in practice are used to illustrate issues that emerge from the study. These illustrative quotes from transcripts contribute to a 'thick enough description' to facilitate an understanding of my interpretation which might both help readers to determine the truth, and usefulness, of research findings for themselves (Kahn, 2000a p.92). In this way, implications for practice are not wrapped in mystique, but use a common language to enable understanding of findings and by implication, potential development in this field.

Another way of opening up the usefulness of qualitative findings to others is by what Steeves (2000) calls '*thinking with the data*'. He argues that the value of investigating human experience needs to be acknowledged in relation to thinking about the human condition in its largest sense. This is achieved by discussing the research findings in the context of other studies. Hence, in imbuing the discussion of this study's findings with relevant literature and research they may be useful to researchers, theorists or '*anyone with the intellectual curiosity to care about these issues*' (p. 98).

7.8 Summary of key issues

In belonging to a supportive team within an end of life care environment, anchored in their beliefs, and armed in being open in communication, participants were readied, and able, to grow in experience of staying alongside patients who were suffering, and in so doing, facing real life and death issues of existence. This study adds to current knowledge and understanding in illuminating how this experience has contributed to increasing spiritual maturity in the nurses who participated in the study, and how that growth facilitates proficiency in spiritual care.

Loss as a spectrum

- It is not surprising that each practice context reflected different issues of loss given that patients in these environments were largely at different points in relation to their end of life trajectory.
- Protocols for addressing end of life care that include spiritual care, adapted for each of these practice contexts, have been made available in published literature.
- The impact of loss on participants affirms current knowledge in relation to the emotional responses that end of life care situations evoke.

Belonging as the means of maintaining spiritual integrity in situations of loss

- Participants team cultures differed across practice contexts in the style of support sourced within the teams.
- Paradoxically, immediate access to support was available for nurses most experienced in their exposure to end of life care, whereas for nurses with less exposure to end of life care, and therefore less experience, access to support was delayed.

Belief as the pillar of spirituality

- Participants' personal experience of belief has been a significant resource in their encounters with loss, and has impacted their aptitude for spiritual care.
- The search for meaning in situations of loss varied and was complex. Possibilities included, man's '*will to meaning*', '*relational consciousness*', critical distancing and re-approaching religion, narrative as a tool for meaning making, retrospective reappraisal or forgiveness, transcending the perception of human control, and the positive focus of living 'in hope' ingrained in hospice philosophy .
- Specific education promoting a more thorough understanding of belief imbued in practice would facilitate a broadening of perspective on the role of belief in meaning making. This may facilitate, not only recognition of patients' struggling with meaning, but also, help nurses

understand what might constitute appropriate support, and so, enhance nurses' development and proficiency in spiritual care

Being a “spiritual carer”

- On occasion nurses ‘looked at’ patients, as a spectator, to maintain perspective, but more often participated in the relationship ‘with’ patients, in being concerned, and being present.
- Communication whether through ‘languages of love’, ‘connected response’, or alternative uses of language, such as, metaphor, were all skills that benefited from an ‘openness’ in style, that involved sharing of self and connecting with something deeper in people. The implication from study findings is that this openness to deeper connection with others can be learnt, and consequently, contribute to nurses spiritual development and proficiency in spiritual care.

Becoming proficient in spiritual care

- The development of spirituality is through experience. Spiritual development results in an increasing maturity in awareness of spiritual matters. Hence, nurses who become more spiritually mature are a resource in helping patients engage with their own spirituality.
- Spiritual maturity was evident in nurses not distracting from existential issues in the use of ‘chatter’, by their awareness of their own vulnerability and the need for personal replenishment and spending time in the ‘clearing’, as well as drawing on their nursing colleagues for emotional support. In addressing their own emotional needs nurses were able to become deeply involved in caring for patients, and exhibit proficiency in spiritual care. The implication for developing spiritual maturity is therefore, discipline in self care.

The effectiveness of methodology; benefits and limitations

- Heideggerian hermeneutic phenomenology proved to be an effective methodological approach in achieving the aim and objectives of the study.

- My use of intuition in interpretation of data has been acknowledged and ameliorated by reference to literature and research that argues that feelings are powerful catalysts for reasoned activity.
- Purposive sampling has also been explained and a rigorous account of sample size presented.
- Transparency of account of my prior experience that has influenced my interpretation of data, coherent rationale for methodology, clarity in description of method, supported by accounts from my research journal, are offered as evidence of trustworthiness as a means of determining this qualitative study's validity.
- Finally, the usefulness of this study has been considered in terms of transferability.

The potential implications of these key issues for practice, education and research are addressed in the following concluding chapter.

Chapter 8

Conclusion

8.1 Introduction

This study focused on nurses' experience of utilising spirituality as a means of helping patients to cope with loss associated with terminal, or chronic disease. It differs from previous studies in providing a different perspective, in particular, examples of how nurses' development may render them not only a spiritual resource in themselves, but also, contribute to how they become proficient in spiritual care in situations of loss.

An Heideggerian hermeneutic phenomenological approach was the chosen methodology for the study. Twelve nurses, five from hospice, four in community practice and three employed within a nursing home participated in semi-structured interviews, in which, they were asked to share their experience of spirituality in relation to situations of loss. A stepped approach to the analysis of interview transcripts facilitated a methodical approach to engaging with, and interpreting, the meaning of the accounts of 'lived experience' described by the nurses. The understanding that has emerged does not constitute absolute knowledge, firstly because of the influence of my own historical situation, outlined in Chapter 3, and secondly, because it can only be partial, in that, I have been interested in the truth seated in the particular experiences of the nurses I have interviewed. However, the '*possibilities projected in understanding*' (Heidegger, 1962 p.189) that have emerged from study findings are developed in discussion in Chapter 7 by drawing on existing theoretical knowledge and concepts. In this way, their usefulness is opened up to '*anyone with the intellectual curiosity to care about these issues*' (Steeves, 2000, p. 98).

Although practice context determined to some extent the nature and intensity of their experiences of loss, and similarly, the differing team dynamics determined their style of finding support, interpretation of nurses' accounts of their experience do have implications for practice and education which are addressed in this chapter. In addition nurses' touched on 'what else is going

on' in practice and as a consequence, comment on potential further research is also included.

8.2 Spirituality as a resource

There were four overriding ways in which participant experience illustrated how use, and development, of spiritual resources helped them cope with recurrent exposure to loss, as well as, support patients' spiritual needs in end of life care

- Fundamental to nurses coping with the emotional demands of end of life care, and their spiritual development, was belonging to a work culture that permitted cultivation, and nurture of spirituality, and so, enabled reciprocal peer support.
- The relevance of belief in making sense of situations of loss was evident for both nurse and patient. Belief in hospice philosophy imbued end of life care practice with a sense of living 'in hope'. Study findings imply that nurses needed not only to clarify their own spiritual stance if they are to support patients in spiritual care, but would benefit from a more in depth understanding of the role of belief in meaning making. Improved understanding may enhance their spiritual development and provision of spiritual care
- The nature of the nurse patient relationship, and means of communication, demonstrated a certain way of nurses 'being' with their patients that constituted spiritual caring. 'Openness' as a particular style of communication within nurse patient relationships involved sharing of self and connecting with something deeper in patients. The implication from study findings is that this open style of communication can be learnt, and so contribute to nurses spiritual development and proficiency in care.
- Nurses who develop the means of protecting themselves, who address their own emotional needs, and so, are able to cope with the trauma of

end of life care, reflect a maturity that enables them to become deeply involved in caring for patients in situations of loss. The implication for developing spiritual maturity is therefore, discipline in self care.

8.3 Implication and recommendation for practice

If nurses are to offer spiritual care it is vital that they too receive appropriate care (Morrison and Burnard, 1991). Study findings illustrate a paradox in the availability and need for support in end of life care settings.

Hospice nurses experience of end of life care is 'intensive' in that all patients are terminally ill and many have challenging symptoms. Fortunately, the ratio of registered nurses is high and so the potential for peer support availability at any one time is strong. Community nurse experience of end of life care is strengthening as health policy due to 'sicker patients...living longer' (Thomas, 2003 p.29) results in increasing numbers of patients, with complex needs, being cared for at home for longer rather than being admitted for institutional care. The ratio of registered nurses to patient is therefore relatively robust, but the availability of support is more nebulous in that it is sourced by catching peers 'back at the office'. Nurses employed in the nursing home accommodate patients' gradual decline into end of life situations with staffing ratios primarily designed for general care. Registered nurses would bring some experience of situations of loss to the nursing home, given that pre registration education of nurses inevitably involves encounters with situations where patients are dying or death actually occurs. However, the presence of any experience is diluted by support workers who have not necessarily had any experience of end of life care. Consequently, when patients are in the advanced stage of a chronic illness the responsibility for support falls heavily on the registered nurse in charge of 'the floor' at the time. Any support the registered nurse might need due to the emotional demands of end of like care situations is delayed, due to low ratio and location of other registered nurses on different floors.

Therefore as the intensity of facing the challenges of end of life care is reduced across practice environments, so is the experience of staff in dealing

with these situations, and yet, it is in these settings that nurse peers as a source of support are mostly a virtual presence. Hence, a significant implication for practice is the need to strengthen a collegial team ethos of support in community and nursing home settings. The recommendation to enhance collegial support in these settings is through more innovative use of clinical supervision.

Reference to individual clinical supervision by one participant from the nursing home setting reflected the apparent failure of this activity to address any restorative function of managing and minimising occupational stressors, issues of particular importance in end of life care practice. Johns (2000) outlines the characteristics and skills needed by a clinical supervisor to create a climate in which a practitioner can feel safe to disclose experiences they would like to explore. Issues of measurable, outcome driven practice exemplify what Schon (1987) describes as problems of the 'high ground' (p3). These are manageable as solutions lend themselves to research based theory and technique. However, questions for exploration in those seeking restorative support are more likely to be from what Schon (1987) describes as the 'swampy lowland' (p3) where messy, confusing problems of greatest human concern defy technical solution. Managerial agendas major in the technicalities of efficient and effective care. Therefore it is not surprising that they may find the comprehensive nature of the role of clinical supervisor difficult (Nicklin, 1997; Johns, 2000). A consequent recommendation is therefore that key to authentic use of supervision as restorative support is the effective preparation of a practitioner committed to the ideals of the role, rather than left to line management as a token of compliance to an acknowledged need.

In contrast, one participant's very enthusiastic description of group supervision sessions open to hospice staff clearly indicated how very much these had been valued. The group was interprofessional and well attended. Its strength in being chaired by a clinical psychologist from outside the institution avoided any power issues that potentially inhibit group function (Hall, 2005), and so cemented the collegiality of the group. Unfortunately, this also proved

to be the group's weakness, in that the cost of buying in an outside chairperson became prohibitive and resulted in its demise. However, this generates another recommendation for the development of practice. Group supervision could be offered as a means of promoting and strengthening collegial support in the nursing home and community team respectively. As before, the preparation of a suitably committed practitioner would be crucial to the success of this development and initiate collegiality in already being a member of the nursing team. This would also not incur the prohibitive cost of buying in an outside facilitator.

8.4 Implications and recommendations for education

8.4a Continued dissemination of hospice philosophy

Hospice philosophy incorporates not only the concept of holistic care in practice, but also, a commitment to the dissemination and development of end of life care practice through education and research (Twycross, 1999). One of the values of education in hospice philosophy is the development of a belief in a different style of practice. This comprises a shift in worldview that embraces the paradox of end of life care in acknowledging that the '*extremely harrowing*' can be '*very rewarding*' (Twycross, 1999 p.166). In this way, a professional worldview primarily focused on the recovery of patients, which generates an attitude of 'there's nothing more than we can do' in situations of end of life care, shifts to one of living in hope of 'there is always something that can be done'. Ultimately, this may be the therapeutic sharing of self as one human being with another. In this way, nurses' use their hope of helping as a spiritual resource. Participants benefited from accessing local hospice educational provision which taught the fundamentals of this philosophy. Some nurses went on to more comprehensive study to achieved higher education awards in, or relevant to end of life care practice. Consequently, the continued provision of unaccredited courses provided by local hospices as a source of initiation, affirmation, and potential springboard for further development, in end of life care philosophy and patient care is recommended.

8.4b Education forums as a means of facilitating spiritual development

8.4b(i) Understanding the role of belief in meaning making

Educational settings provide the space for either initiating reflection on, or review of personal spiritual stance. Study findings demonstrate that belief has been a significant resource in nurses' experience of loss, and has impacted their aptitude for care. Consequently, rather than just being encouraged to clarify their own spiritual stance, nurses may also benefit from a more extensive exploration of the role of belief in meaning making. If, for example, participants had shared their narratives of spiritual journey in an educational forum they would have known that their stories followed a similar pattern. Understanding patterns of belief may develop their ability to recognise this in others. Review of literature and research that illuminates the complexity of the human need to search for meaning, as well as, tools, such as, narrative, that facilitate meaning making would enhance nurses theoretical base for spiritual development of practice.

8.4b(ii) Style and communication, being 'open' and spiritual maturity

Being available as a spiritual resource is rooted in what Morse et al (1992) describe as reflexive or 'connected' response to human suffering, such as consolation, compassion and commiseration. These automatic responses are culturally conditioned and exist prior to formal preparation to nurse. Hence, a recommendation for education is that, a strong emphasis on the value of this predisposition to reflexive response is included in teaching communication skills as a subject of professional practice. This could be facilitated by experiential learning to develop the skills that enable therapeutic nursing presence, in much the same way as Culliford (2011) describes the experiential activities of medical students to use 'deep presence' through active listening, 'watching' for visual clues, and setting the emotional tone of conversation with patients.

8.4b(iii) Discipline in self care

Maturity in becoming a professional in spiritual care includes the extent to which the nurse knows and can manage her involvement within therapeutic relationships with patients. Johns (2000) advocates that structured reflection is a means of knowing the self, *'even in its deepest darkest corners'* (p.69), and

so, an implication for education is to empower nurses with the skills to choose and use a model of reflection that best suits their mindset. However, educational settings also provide a safe haven for issues of balancing professional practice and personal life to be advocated, and the means of achieving this shared or discussed. The importance of taking time out to reconnect with the self as a means of spiritual replenishment is easily said, but not so easily achieved when what has to be ‘done’ in both contexts seems to consume time, leaving no space to just ‘Be’. The means of returning to ‘Being’ or metaphorically spending time in ‘the clearing’ can be impromptu, for example, pottering in the greenhouse or more formally arranged in retreat. Culliford (2011) suggests a range of examples of spiritual skills that can be learnt through practice, such as stilling the mind through meditation, and contemplation. A crucial recommendation is therefore, that education settings provide a forum to encourage discussion regarding the importance of a disciplined approach to spending time in ‘the clearing’, to raise awareness of the many ways this may be achieved and to emphasis the value of such activity as a spiritual resource for personal growth and professional practice.

8.5 Implications and recommendations for further research

Implications for further research that may benefit both practice and education are indicated by findings that illuminate ‘what else is going on’ alongside the focus of this study.

In situations where patients had mental health disorders as well as end of life care needs participants described experiences that exemplified the challenge of fully meeting these patients’ needs. They lacked the skills and experience of mental health nursing and in one particular instance, there was a sense of being abandoned by mental health services. Publications indicate the potential gap between end of life care and mental health provision (e.g Quails and Kasi-Godley, 2011). Dilemmas are posed by patients who are mentally ill and then develop end of life care needs, as well as, by patients who become mentally unwell because of the circumstances of their being in an end of life care situation. A recommendation is therefore, for further research focused on this rift in service, identifying causative factors that might lead to an

understanding of how best to promote better interprofessional working for both teams of nursing professionals in the best interest of their end of life care patients.

Metaphor was used by a number of participants as an effective means of conveying depth of feeling when describing their experiences. In reconciling life's experiences with existential questions metaphor provides a way for people to think about and interpret their world, to make sense of it. As a form of figurative speech that provides insight into hidden meanings within language (Froggatt, 1998), metaphor is described by Czechmeister (1994) as more than a '*linguistic ornament*' (p.1229), but as a potential source of knowledge of a different nature for nurses, a window on the experiential 'lived world' of the patient. The word metaphor is derived from the Greek for 'go beyond' (p.1232). The essence of caring in end of life care situations is to maintain the '*wounded personhood*' (p.1232) of the patient which requires understanding their feelings that are often '*beyond words*'. Consequently, another potential question for further research is does professional education sensitise nurses to metaphor as a gateway into the perceptual world of those facing illness?

8.6 Conclusion

Spirituality is not limited to one discrete dimension of being human but concerns the whole of a person's ongoing effort to integrate their life. End of life care situations bring life's ultimate concerns into sharp focus (Twycross, 1999). This study has reflected how nurses who participated, and shared their 'lived experience' of caring for those with end of life needs, utilised spirituality as a resource in coping with loss in these circumstances. Belonging to a supportive team within an end of life care environment, belief as means of making sense of experiences of loss, together with, 'openness' in communication style, that involved sharing of the self and connecting with something deeper in patients, made possible by nurses addressing their own emotional needs, collectively, enabled nurses to grow in spiritual maturity and exhibit proficiency in spiritual care.

Implications for practice concern the benefits of collegial team dynamics and more effective use of clinical supervision. The value of education in the fundamentals of holistic philosophy, that involves addressing spirituality and loss in end of life care practice, was evident. Further implications for education include promoting an understanding of the role of belief in meaning making, nurturing, rather than neglect, of automated culturally conditioned responses to human suffering within experiential learning to facilitate 'connected' communication skills, and also, engendering a disciplined approach to metaphorically 'take time out in the clearing' to reconnect with themselves. Clarification on the cause of dilemmas of mental health care needs, in, or that emerge from, end of life care situations is worthy of further research to enable future practice development. Similarly, investigation of nurses' sensitivity and understanding of the use of metaphor may illuminate how particular aspects of nurse-patient relationship and communication, could be developed to enhance spiritual care further.

Rigour in relation to this study has rested on the principles of logic in relation to persuasive argument as appropriate for qualitative research (McLeod and Wright, 2008). The research strategies used throughout have endeavoured to promote transparency of method, including some analytic originality in adding a further step to the tool used for analysis. Findings are couched in terms that enable understanding, and so, although not generalisable, may be found of interest to others in this field.

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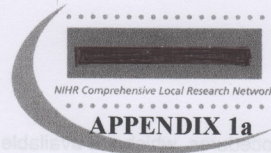
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APPENDIX 1a



NHS
National Institute for
Health Research

Comprehensive Local Research

Tel: [REDACTED]
Fax: [REDACTED]
Email: [REDACTED]

Mrs Wendy Greenstreet
Faculty of Health and Social Care
Canterbury Christ Church University
North Holmes Campus
Canterbury
Kent, CT1 1QU

21st May 2009

Dear Mrs Greenstreet,

Letter of access for research

Re: Understanding psychosocial and spiritual issues in relation to coping in situations of chronic or terminal illness. (Project 09/028P)

This letter confirms your right of access to conduct research through [REDACTED] PCT for the purpose and on the terms and conditions set out below. This right of access commences on 21st May 2009 and ends on 21st May 2012 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation.

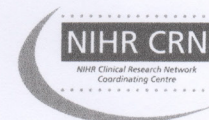
The information supplied about your role in research at [REDACTED] PCT has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out. Please note that, this letter does not confer any rights of access to patients of [REDACTED] PCT.

You are considered to be a legal visitor to [REDACTED] PCT premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through [REDACTED] PCT, you will remain accountable to your employer Canterbury Christ Church University but you are required to follow the reasonable instructions of [REDACTED], Modern Matron to the [REDACTED] PCT Rapid Response out of hours team, or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

Directors: [REDACTED] 233
Hosted by: [REDACTED]



The [REDACTED] Comprehensive Local Research Network operates as part of the NIHR Comprehensive Clinical Research Network in England. It is part of the National Institute for Health Research and forms part of the UK Clinical Research Network. The Networks support and deliver high quality clinical research studies.

You must act in accordance with [REDACTED] PCT policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with [REDACTED] PCT in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on [REDACTED] PCT premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

[REDACTED] will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

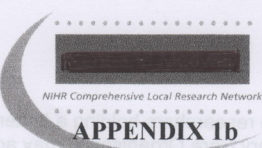
If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.


Yours sincerely








Dr. [REDACTED]
Research Management and Governance Coordinator, [REDACTED] PCTs

Copies to: [REDACTED] to forward to HR, [REDACTED] PCT
[REDACTED] Human Resources, Canterbury Christ Church University, North Holmes Road
Campus, Canterbury, Kent, CT1 1QU

APPENDIX 1b

**APPENDIX 1b**


National Institute for Health Research

Comprehensive Local Research Network for 



Tel: 
Fax: 
Email: 




Reference: Proposal 756 (Project 09/028P)/Approval Letter/version2 (r appendix v2)

Mrs Wendy Greenstreet
Faculty of Health and Social Care
Canterbury Christ Church University
North Holmes Campus
Canterbury
Kent, CT1 1QU

30th November 2009


Dear Mrs Greenstreet,



Re: Understanding psychosocial and spiritual issues in relation to coping in situations of chronic or terminal illness

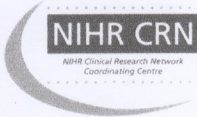
I wrote to you previously (26/03/2009) to inform you that the above-named project had been approved by  Community Services for work involving interviews with their staff. That approval applied to the  locality of  PCT. You now wish to extend the study to other localities in the PCT. This letter is to inform you that the study is approved for all localities listed in the appendix to this letter. The appendix may be updated by us from time to time as you present me with evidence of other locality managers authorising your research in their areas.


This approval requires that the work is carried out in accordance with the principles set out in the Research Governance Framework for Health and Social Care (Second Edition, DH 2005) and the Data Protection Act (1998). The current version of the Protocol is Version 3 (19/10/08). The CLRN (see contact details in the header of this letter) should be informed immediately if any of these criteria are to be changed.

Conditions of Approval

- 1. Sponsorship of study**
Canterbury Christ Church University will act as research sponsor;  Community Services is not responsible for the design and conduct of the study.
- 2. Confidentiality**
You are required to ensure that all information regarding participants remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the Data Protection Act (1998) and the NHS Confidentiality Code of Practice (www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf). Furthermore, you should be aware that, under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

Directors: 
Hosted by:  235


NIHR CRN
NIHR Clinical Research Network
Coordinating Centre

The  Comprehensive Local Research Network operates as part of the NIHR Comprehensive Clinical Research Network in England. It is part of the National Institute for Health Research and forms part of the UK Clinical Research Network. The Networks support and deliver high quality clinical research studies.

3. Researcher authorisation

Important. Only those researchers holding a Letter of Access from the Primary Care Organisation may access the Trust's premises in order to interview the staff participants of the study.

4. Study progression

You will inform me of any significant developments that occur as the study progresses, including notifying me when the study has been completed and sending me the final report and details of any publications, dissertations, abstracts etc., which may result from the study, so that our records can be kept up to date.

Finally, I wish you continued success with the study.

Yours sincerely

Dr [redacted]
Research Management and Governance Coordinator, [redacted] PCTs
copy to: [redacted] as above.

APPENDIX 2

Topic Guide for Interview

Introductions

Initial conversation to set context/help interviewee be at ease/ lead into focus of interview – important interviewee understand no right or wrong answers but share the reality of their ‘lived experience’ – their narrative.

Topics:

Spirituality

What does the term spirituality mean to you?

Potential prompts/clarification/exploring responses further:

-for herself/himself-within her/his working context

How have you arrived at these understandings?

e.g. education/clinical assessment/experience/family values and beliefs

What are your perceptions of spiritual need in practice?

e.g. evident/incidental/implicit/patient self sufficiency

What experience have you had of spiritual care/support in practice?

examples of these?

Loss

What do you understand by the term loss in relation to your work?

Potential prompts/clarification/exploring responses further:

e.g. inevitable, cumulative, related to death, related to disability

What experience do you have of the issues that evolve in situations of loss?

e.g. despair, hope, perseverance, ultimate/existential question

Give an example of a situation in which loss occurred

-how did you deal with this?

-on reflection is there anything you would change now?

Personal Resources

How do you deal with loss on a day to day basis?

Potential prompts/clarification/exploring responses further:

e.g. therapeutic use of self, professional - more detached approach, referral

What resources do you have personal access to as form(s) of support

e.g professional support, personal resources

Do you have a religious faith?

e.g which religion?, practicing?

Version 2 September 2008

APPENDIX 3 Example of interview transcript

Emergent Themes	Transcript 8	Exploratory comments
Religious and non religious faith	<p>Q: Thanks very much for agreeing to take part in this interview. There are three areas we are going to explore; spirituality, loss and personal resources. So firstly I'm particularly interested in what you think is meant by the term 'spirituality'?</p> <p>A: Hmm, it's quite a difficult one, really. <i>I think that's changed over my lifetime, I think I used to... as a child I was brought up with quite a strong framework of religion, a Baptist background, my father was a minister of the religion. So I had a very sort of structured framework for my spirituality, and I guess my spirituality was very attached to that faith and belief. But as I've grown older, gradually it has become more nebulous, really I guess. More... I sort of... I think your religious framework is still quite important to your spirituality but spirituality is greater, it's bigger than the religious framework. And so I think I've described before, when I was a child, I had very deep roots. Those roots are still there, but the branches are slightly different, you know, the outward appearance is slightly different. So my sense of spirituality has changed enormously because of that.</i></p> <p>Yes so I mean for me, spirituality is about how you connect to other people, to God, to Nature, to... it's about connection, it's about belonging, it's about feeling a</p>	<p>Changed over lifetime</p> <p>As a child strong Baptist background Father minister</p> <p>Structured framework for spirituality – very attached to that faith and belief</p> <p>As older- gradually more nebulous</p> <p>Religious framework still important to spirituality but spirituality – greater- bigger than religious framework</p> <p>So sense of spirituality changed enormously</p> <p>Spirituality is about how you connect with people, God, nature <u>Style of relationship</u> About belonging</p>

<p>Religious and non religious faith</p>	<p>part of things really, I guess that's my definition I suppose.</p> <p>Q: What about in relation to work? That's your personal belief, so spirituality in the context of working here, for example, in a hospice? How would you interpret that in practice?</p> <p>A: Well obviously when you're caring for someone there's a connection there, and it's very easy – we've got tasks that we have to do, so we may have to wash them and have to do whatever, and most tasks are physical things that we have to do as part of our work. But it's the 'how you do it' that defines spirituality. So there are...you can go in and chivvy someone along and get them dressed and washed and all the rest of it, and do it quickly and you haven't connected with that person. But if you go with ... what I feel ... a spiritual context, what you do is actually very spiritual. So giving someone a wash is actually very spiritual and it's because of that, how you might do that, it's about being gentle, being sensitive, about being aware of that person's embarrassment and their nakedness. And the whole touch, touch is really important. And how you go about that, and the conversation you have with that person as you're going through the process, that's spirituality. I guess. <i>So it's really making that connection with that person and acknowledging that person is a human being just like yourself, with an amazing amount of history behind them,</i></p>	<p>When you are caring for someone there is a connection there</p> <p>'how you do' work that defines spirituality</p> <p>So giving someone a wash is very spiritual</p> <p>Being gentle, being sensitive</p> <p>Touch is really important</p> <p>And conversation you have with that person as you're going through process</p>
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	<p><i>just like you have, and that somehow your two souls have come together and there's a connection there. I guess that, in reality, is what I see as spirituality in the practice.</i></p> <p>And making sure that people sense that they are human they're more than just this body that needs to be washed. There's something greater than that, that individual. I guess that's the way I see it really.</p> <p>Q: Yes, I mean I think that's helpful. I'm interested in the souls coming together, that sort of implies a reciprocal response. Are there situations in which you've found that it's not possible to connect?</p> <p>A: Of course, yes. And you can't connect with everyone, but if you go in with the attitude that you want to acknowledge and connect and meet someone at a deeper level, invariably it will happen and even with the most difficult people it will happen. It's about your own... where you're coming from, and I guess it's about your own attitude. You can't do much about how other people behave and their attitude, you can about your own and how you approach them, it can make a massive difference to the connection that happens there. Even someone you wouldn't normally naturally relate to or might not have an understanding of where they're coming from, so I think that's important.</p> <p>Q: Can you think of a situation where it's been</p>	<p>Somehow your two souls have come together and there's a connection there <u>Relationship- reciprocal</u></p> <p>They're more than just this body</p> <p>Can't connect with everyone But if go in with the attitude you want to - connect – meet someone at deeper level – invariably it will happen</p> <p>Can't do much about how other people behave and their attitude – you can about your own and how you approach them – can make a massive difference to the connection <u>Remain open</u></p>
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	<p>difficult to connect and if you have been able to... by the way you are... change that, or not?</p> <p>A: I'm just trying to think...</p> <p>Q: Sometimes things stick out in our mind as particularly difficult or particularly good?</p> <p>A: Yes. I think, when I was working at *****, I shouldn't say that because this is confidential!</p> <p>Q: So that's a nursing home?</p> <p>A: Yes it's a hospital, actually, a Christian hospital the other side of ***** *****, and I remember we had this lady came in who... I can't remember why she came in, but she was a very difficult lady and everyone was coming out of the room and looking really angry and cross, and I thought oh goodness what's going on, and everyone was saying oh she's a cantankerous old woman and you couldn't do anything right for her, blah blah blah. And I thought oh right, and it was my turn to go in there and give her some medicines so I walked in with the trolley and I thought well I've got to try and make an effort here, and it was really tough, it was difficult, but I maintained that positive... I tried to be really positive and I tried to meet her halfway and tried to see things from her point of view a little bit. And I think very soon I realised that she was just reacting to all the changes that were going on in her life, she couldn't cope with</p>	<p><i>Humour in slipping up re naming past institution</i></p> <p>A very difficult lady</p> <p><i>Humour 'oh goodness'</i></p> <p>I thought - I've got to try and make an effort here</p> <p>It was really tough, but I maintained the positive</p> <p>Tried to meet her halfway, tried to see things from her point of view - soon I realised she was just reacting to all the changes that were going on in her life</p>
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	<p>all the changes and suddenly to be admitted to hospital, and behind all of that there was a very lovely person who was just very stressed at having been admitted in to hospital to a strange environment and lots of different people coming into her room and stuff. So it just took a while to connect and then to take stock and look back and try and see the bigger picture, and then she actually – once she'd settled that first day – she was fine and everyone seemed to relate quite well to her, but it was difficult.</p> <p>Q: How did you find her, when you went in with the medicines?</p> <p>A: Well she looked sort of officious and very ... you know, everything had to be perfect. And there was a coldness about her. And she was quite short with you, do this, do that, you know. There was that sort of feel to her and you could sense the sort of anger. But that slowly melted away.</p> <p>Q: Did it melt away ? ... You said first day, by the end of the day...?</p> <p>A: By the end of the day, I think it was just the persistence of staff going in and just trying to maintain that positive attitude and not allowing that to escalate in some ways you know. And then trying to listen to where she was coming from.</p> <p>Q: So the team - were doing the same? It wasn't that they were approaching it differently?</p>	<p>She was just very stressed</p> <p>So it just took a while to connect and then take stock and see the bigger picture</p> <p>She settled after the first day</p> <p>Officious</p> <p>Coldness about her</p> <p>Could sense anger</p> <p>Just the persistence of staff going in trying to maintain positive attitude</p> <p>Trying to listen where she was coming from</p>
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	<p>A: Yes, I think everyone was... I mean we were all coming out of the room and having a good old moan about her, you know to begin with. But then she was fine, after the first day she was fine. And I think it was because the staff attitude was - we've got to be positive whatever, and we're going to try and connect with this lady and, you know, do the best we can for her.</p> <p>Q: The team must have been quite cohesive? I'm interested that it came out, and you shared the challenge of it... I mean it was a while ago now I'm sure, but collectively do you remember if you were agreed on this woman, what you thought, or were you collectively perplexed by this one lady being particularly difficult?</p> <p>A: No I don't think we had a sort of game plan or anything, but I think it was just the normal philosophy of ***** , it was just the way staff were...</p> <p>Q: Were all the staff Christian?</p> <p>A: No.</p> <p>Q: But I guess they would have been employed having some sympathy?</p> <p>A: Yes, definitely.</p> <p>Q: Sharing the values.. I think probably the example you've given is a difficult situation in hospital, I wonder if</p>	<p><i>Humour 'good old moan'</i></p>
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<p>Rapport and relationship as a spiritual resource</p>	<p>in the context of the hospice here, whether there is an agenda in relation to assessing spiritual needs or whether again it's about absolutely every opportunity, every incidental meeting or care as an opportunity?</p> <p>A: I think... I find I have a problem with the assessment sheets we use here, personally.</p> <p>Q: That's fine it's to do with individuality.</p> <p>A: Yes, and it's a bit prescriptive in some ways, and the questions it's asking... I know it gives a lot of flexibility and it's about... but in some ways I feel spirituality is so broad and wide and deep that you can't begin to start assessing it in those sorts of terms.</p> <p>Q: Tell me about the tool, what is the tool like?</p> <p>A: Well it asks... it sort of gives you hints of questions you can ask, like who are the important people in your life, sort of questions, what makes you feel ... what gives you a sense of... something similar to feeling happy... what gives you a sense of wellbeing, that sort of question. And they are quite open ended questions in that sense. <i>And I suppose you've got to start somewhere. But I find that when you're in with someone, to start asking those sort of questions as a spiritual assessment just doesn't ring right with me. I think you assess someone's spirituality by being with them for a period of time,</i></p>	<p>I have a problem with the assessment sheets we use here</p> <p>Prescriptive</p> <p>Spirituality is so broad and wide and deep you can't – assess – in those terms</p> <p>Gives hints of questions-that-</p> <p>gives you a sense of – something similar to feeling happy –sense of wellbeing</p> <p>those sort of questions – for – spiritual assessment just don't 'ring right' with me</p> <p>assess spirituality by</p>
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<p>Accessing support for patient care</p>	<p>considering situations of spiritual distress, are there any particular examples you've been aware of?</p> <p>A: Here in the hospice? In my experience in general... yes, I mean I remember this gentleman... and <i>there was this gentleman who I remember one morning, normally quite a jolly and happy go lucky chap, but this morning he just seemed really down and quiet... I would say possibly even tormented by something. And you know I went through all, the thing... have you got any pain – no, no pain. We went through everything and there were no symptoms that could account for the fact of the way he was looking. And so I said is there something on your mind? And he didn't say anything, he just kept quiet which obviously meant that there was something on his mind. And I said I'm happy to hear what you say, you don't have to say anything but I'm quite happy to just talk to you about it. And he said I need to see my daughter, and I said right ok would you like me to contact your daughter and he said yes I want to see her today, it's really important. So I said ok I'll do that for you, so I phoned his daughter and said he's a little bit down and he wants to see you, it's quite important so that afternoon she came. He was in a side room, so I took her in there and they had about 1½ hrs together. And eventually she came out, she was obviously in tears and I went in there and he'd obviously been in tears and been really upset, but that</i></p>	<p>Normally quite jolly – but this morning seemed down</p> <p>Even tormented</p> <p>Obviously – something on his mind -<i>humour</i></p> <p>I need to see my daughter</p> <p>I want to see her today really important</p> <p>They had about 1.5 hours</p> <p>She was –in tears</p> <p>He'd – been in tears</p>
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<p>Accessing support for patient care</p>	<p><i>torment had gone</i>, so something had gone on there between them that some reconciliation or what, I don't know. It was very powerful. <i>And when he died</i> she came for the post bereavement, I did the post bereavement, <i>she thanked me for calling her in, she didn't say what it was about or anything, but it was a very significant conversation they'd had and she felt I was able to facilitate that. So I thought that, for me, was a patient in spiritual distress at that point and by doing something very simple – all I could do was just arrange something to happen</i>, I wasn't involved in the whole process, but by just doing that something very powerful happened. So I think that made me...that really sticks in my mind from years ago.</p> <p>Q: A very positive outcome. You started by saying that spiritual care is very much about how nurses are with patients - you also said - nurses can facilitate very simple arrangements that are actually quite powerful in helping somebody. Are there any other ways that come to mind particularly when you think of nurses facilitating spiritual care?</p>	<p>Some reconciliation or what?</p> <p>Spiritual distress</p> <p>Doing something very simple <u>Accessing support</u></p> <p>Something very powerful happened</p>
<p>Rapport and relationship as a spiritual resource</p>	<p>A: <i>I think it's the whole of comforting, you know we're all on a journey and we're all sort of on a journey of discovery I suppose, as the world unfolds in front of us, and in some ways every day is a brand new day and brand new things happen and it's true for our patients and some of those things, those</i></p>	<p>Spiritual care –whole of comforting</p> <p>As world unfolds in front of us</p> <p>some-things-</p>

<p>Rapport and relationship as a spiritual resource</p>	<p><i>new things that happen, can be incredibly overwhelming particularly when people are coming to the end of life. And somehow just to be there alongside them and being on that journey of discovery with them I think is a way of giving spiritual care. So just being able to listen, listen beyond words, listen to what's really coming from somewhere deeper and trying to learn that intuitive ability of actually not just hearing someone's words but maybe having a very practical implication in that words but actually there is maybe something much deeper behind those words. And not necessarily coming to conclusions about that but just being aware of that</i> and having that demeanour to say there could be something much deeper here but I'll just be alongside and if that person wants to talk about that then you're.... so much of it is just about being there <i>and listening in case that person wants to talk through that</i>, and being that fellow seeker, I guess.</p> <p>Q: And that... what you said, that's the difference between being there and open as opposed to prescriptively requiring to find out. That's really interesting - the way you've explained how nurses can be alongside patients - being aware of the deeper issues. In your experience, is that something that ... can all nurses do that?</p> <p>A: <i>I think you can learn to do it. I think some people are naturally more able to do that,</i></p>	<p>overwhelming –when coming to end of life</p> <p>just to be there alongside them – is a way of giving spiritual care <u>'being there'</u></p> <p>being able to listen – listen beyond words – what's coming from somewhere deeper – trying to learn intuitive ability <u>'being with'</u></p> <p>Can learn –</p>
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<p>Rapport and relationship as a spiritual resource</p>	<p><i>just partly their personality or their life experiences that brought them to that point. But I think once you've done it once or twice, once you've actually tried to connect with something deeper in people once or twice, and you see how powerful that is, you get hooked in! And you keep on doing it and it keeps on happening and it reinforces continuously that whole spirituality thing really, so I think it also depends where people have come from, where they've worked, their working background, so you've got some staff who are very efficient and need to get the tasks done, and the task is the focus, and then you've got other staff that actually the task is secondary and the core of a person is much more important, and trying to connect with that. And of course you can't forget the tasks, and that's the difficult thing isn't it, it's trying to find that balance really. Because it's very easy to just suddenly forget about the tasks completely, which is very impractical, I mean spirituality is earthy at the end of the day so actually giving someone a wash is spiritual.</i></p> <p><i>I suppose we're quite dualistic about spirituality and think there's a physical and spiritual or the sacred and the secular, but actually there isn't that divide. It's all one and the whole of life, everything, is all a thread of the same thing really.</i></p> <p>Q: So the tasks are the means really.</p>	<p>once you've actually tried to connect with something deeper in people – you see how powerful that is – get 'hooked in' -humour</p> <p>reinforces continuously the whole spirituality thing</p> <p>some staff efficient and need to get tasks done</p> <p>other staff - tasks secondary and core of person more important</p> <p>Spirituality is earthy</p> <p>Dualistic but...</p> <p>whole thread of the same thing -Staff knit differently?</p>
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Rapport and relationship as a spiritual resource	<p>A: Yes. So you can't ignore the tasks, <i>sometimes those tasks have got to be done and they feel as if they're getting in the way, but actually it's the way you do those that brings in the spirituality.</i></p> <p>Q: Thanks very much. Moving on now to think about loss...in the context you're working in currently, what understanding do you have of the term loss?</p>	Way do tasks – brings in spirituality
Consequences of loss for patients and their significant others	<p>A: Well I mean life is full of losses, you know when you're born you lose the comfort and warmth of being in your mother's womb, that's a loss – as soon as you're born you lose something. <i>Every time there's a change or transition in life there are many losses involved</i> in that. So when the child goes to school for the first time there's a loss there for the mother and the child because they're going in different directions. And a new house, there's a loss there because you lose the physical house you had and move to a new house, but it's not as simple as oh it's just a new house, you do have emotional connections with that old house that you will have lost. So everything in life is saturated with loss really and it's part of moving on in life. And so I guess every day is full of losses. <i>But obviously there are spectrums of loss</i>, you know you've got the little losses but you have the big losses in life, so when you love a loved one that's a major loss and so yes, that's how I see loss.</p>	<p>Life is full of losses</p> <p>Every change/transition there are many losses</p>
Consequences of loss for patients and their significant others	<p>And so I guess every day is full of losses. <i>But obviously there are spectrums of loss</i>, you know you've got the little losses but you have the big losses in life, so when you love a loved one that's a major loss and so yes, that's how I see loss.</p>	<p>Spectrums of loss- <u>differentiation of loss</u></p> <p>Loved one - major loss</p>

	<p>Q: How do you see that exhibited here in those you care for?</p> <p>A: By patients, by staff?</p> <p>Q: Both, really.</p> <p>A: I think there's a natural sadness and you get a natural cry, you get a very different reaction actually.</p> <p>Q: I was interested in the variety of reaction.</p> <p>A: I mean some people – funnily enough, I find it fascinating in children, how they deal with it. I remember when I was working at St Christopher's and there was a young lady who had two girls, they were probably about 5 and 6 years of age, quite young. And they knew their mum was dying, and she died, and they were absolutely devastated, completely and utterly devastated. And you know I found it really difficult to know how to help, it was speechless, how do I deal with this, you know. And 5 minutes later they were outside in the garden, playing with toys, having a good laugh, and it was like 'hold on, what's that like!' I don't understand this! But they've got that way of...they're grieving and then they get on with their life, and then they might grieve again, so later on in the afternoon they were crying again and they were sad and again later on they were playing. So that was a very interesting way of seeing loss in those children in that initial impact. But of course the</p>	<p>Natural sadness Natural cry</p> <p>Fascinating how children deal with loss</p> <p><u>oscillation</u></p>
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<p>Consequences of loss for patients and their significant others</p>	<p>journey obviously is much longer in their loss. But in that initial impact it was quite fascinating to see that in them.</p> <p>Q: They were distracted from the moment by play, then?</p> <p>A: Yes, they were distracted, or just getting on with their life again. And...but then the enormity of it all came back to them and so they... it was fascinating to see that, and I've seen it a few times with children. Not to that extreme, but I have seen that in children. They sort of seem to get on with it don't they. But I mean I've seen... having worked in different cultures as well, how people deal with that loss is very different.</p> <p>Q: Tell me about the cultures you've been in?</p> <p>A: <i>Well I worked in South America in Ecuador, and out there when someone dies it's literally wailing, people collapsing on the floor fainting and incredibly melodramatic and everyone knows, the whole street will know about it and everyone comes and visits and they all cry and everyone's there, and it's just the end of the world, seriously big time! People throwing themselves in the grave and all that sort of stuff, it is pretty amazing. And so I've seen that. And having the wake, people have a wake and everyone from far a field comes and has to pay their respects and that sort of stuff. So that's one extreme, and then the other extreme is where you see people in this country</i></p>	<p>Different cultures-people deal with loss in different ways</p> <p>Ecuador-</p> <p>wailing and collapsing on the floor Melodramatic Whole street know All visit and cry</p> <p>People throwing themselves in the grave-humour</p> <p>Wake everyone from far a field come to pay their respects</p> <p>in this country its done</p>
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<p>Consequences of loss for patients and their significant others</p>	<p><i>who... it's done and dusted, and they have to go on and get themselves busy sorting out what do we do now, this kind of no emotion shown and they have to get on with their lives and they have to get on with tasks of sorting out what's the next thing to be done. So there are extremes of reaction to loss. And that's not to say that either one or the other is right or wrong, it's just the way cultures and societies and personalities have formed that person to react in that way.</i></p> <p>Q: We can learn from other cultures can't we. Within the sort of culture that's represented here, have you seen very different responses in that way?... have you had any wailing here?</p> <p>A: Here in the hospice I can't remember... well I've heard people crying loudly, definitely, yes. But I wouldn't say it was like literally shrieking and wailing. But when I was at St Christopher's we did have an Afro-Caribbean family and they wailed and screamed and shouted, and it was pretty full on, it seriously was. But <i>here in this hospice I think we don't have that much of a cultural mix</i>, it tends to be... I mean ***** isn't... I mean ***** <i>is much more of a cultural mix</i> there, I think ***** isn't so much. <i>But even within English culture you've got a spectrum of response to it.</i></p> <p>Q: Yes we have, have you seen examples of that here?</p>	<p>and dusted – busy sorting out what do we do now-no emotion shown-have to get on with their lives</p> <p>extremes of reaction to loss</p> <p><u>comparison of cultural response</u></p> <p>Afro Caribbean family wailed and screamed and shouted <i>laughter</i></p> <p>Even within English culture you have a spectrum of response</p>
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<p>Faith as a resource to regulate distress</p>	<p>A: Yes I have, I've seen people...not to the extremes like I was talking about, but you know people crying out very loudly and being very demonstrative in the way they're upset by it, yes I've seen that.</p> <p>Q: Much more explicit in their grief then? Open about their distress rather than controlled?</p> <p>A: Yes. So you do see that, there's a spectrum in our own culture.</p> <p>Q: Is there a situation here that has been particularly distressing relating to a loss, either for staff or for the relatives?</p> <p>A: <i>I think it's always difficult when there's young people who die. And when I worked in Ecuador I worked in a unit there with HIV and aids and in the early days there weren't the anti-virals and young people were dying very young, you know. And that really feels as if someone's been stolen away and that's really tough. And I find that tough with young people, if someone younger than me dies it really hits home, you know, it shouldn't be happening.</i></p> <p>Q: How is that managed? How is it possible for nurses to help, in your experience, people who are in that situation, dying and young, and their relatives who have a particular loss, an untimely loss of a young death?</p> <p>A: Well I think this whole</p>	<p>Crying out very loudly and being angry <u>Open about distress and less controlled?</u></p> <p>Difficult when young people die</p> <p>Feels as if someone's been stolen away</p> <p>If someone younger than me dies it really hits home</p>
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Meaning and purpose	<p>thing of <i>being there that's really all you can do, you can't say anything can you. The moment you say something it's a platitude and if you think you've got the answers you're in the wrong job basically. You know, you've got to admit that there aren't any answers to certain things. And you may have certain answers for yourself but they may not be right for someone else</i> either.</p> <p>So it's all about just being there and just absorbing some of that.</p>	Being there that's really all you can do
Informal support for nurses	<p>But also <i>being in touch with your own feelings, I think the worst thing you can do in this job is to bury it and just to ignore it, you've got to reflect on those feelings and be in touch with those feelings and find ways of expressing them, but quite often because you're a member of staff there's that sense that you've got to be coping and getting on with... you can't be showing your feelings to relatives but somehow you do need to do that in an appropriate way and making sure that there is a facility to be able to do that. And I think with staff it's about supporting each other and allowing each other to cry if we need to, things like that.</i></p> <p>Q: We've actually quite nicely led on to the third area – personal resources, really, in managing and helping people who are suffering loss and dealing with their distress you've inferred that there's peer support with staff and, you know, permission to cry. You also said yourself that it's to do with reflecting on your own feelings and also you</p>	<p><i>Humour</i> wrong job</p> <p>Aren't any answers to certain things</p> <p>Being in touch with your own feelings – not bury it and ignore it</p> <p>Find out ways of expressing them</p> <p>Do need to show feelings to relatives in appropriate way</p> <p>With staff its about supporting each other and allowing each other to cry if we need to <u>Peer support</u></p>

	<p>mentioned about how there are no answers.... we started with you having a religious faith – does that help?</p> <p>A: Yes and no! Having a religious faith...</p> <p>Q: That’s an interesting answer that I’m bound to explore, both issues yes and no.</p> <p>A: Yes and no. It is a yes and no. Because <i>another way of looking at spirituality is that search for meaning isn’t it, I think Frankl talks about the search for meaning, and I think we are all in that search</i> and I’ve talked about <i>the journey of discovery</i>. And <i>I think it was Nietzsche who said that he who has a why to live for can cope with almost any how. So to have some reason to live for is very important, and your faith can bring that, and can give you a certain rock to stand on,</i> it gives you foundations to structure life on, and that can be very helpful. <i>But then there’s the flipside of that, if you have got a faith and things happen in the world that rub against that faith hard, it can really be very difficult to handle that. And I certainly found that in my work, it’s opened up all sorts of questions about my faith, about my beliefs, and those as the years have gone on have been refined tremendously. I think that’s just part of growing up anyhow, to be honest. But working in patient care and working in an HIV unit, some of the things I’ve seen and some of the experiences I’ve had through all that have knocked me and knocked my faith and</i></p>	<p><u>Humour in contradiction</u></p> <p>Spirituality is that search for meaning</p> <p>That search –the journey of discovery He who has a why to live can cope with almost any how</p> <p>Your faith can bring reason to live</p> <p>If you have a faith – things happen to rub against that faith hard</p> <p><u>Humour</u> questions about faith</p> <p>Some of the <u>practice</u> experiences I have had have knocked my faith <u>faith challenged</u></p>
Meaning and purpose		
Faith as a resource to regulate distress		
Faith as a resource to regulate distress		

<p>Faith as a resource to regulate distress</p>	<p><i>made me really have to reflect and rethink and come to new understandings and that's quite painful sometimes.</i> A difficult thing.</p> <p>Q: How do you cope with that? Obviously through reflection yourself? Have you found any other help?</p> <p>A: <i>I think it's just arriving at that point where you just have to embrace uncertainty really, you can't say anything is black or white.</i> You know, you've got to actually just be open to whatever, really. So you know as a child and as a young adult I had a very structured faith, that structure is much more loose, much looser now. And I'm happy to question some fundamentals my faith has struggled with those and come to new understandings of things. And ...</p> <p>Q: Do you mention this with others who have similar faith, do you have a... or is it just for yourself?</p>	<p>come to new understandings – a difficult thing</p> <p>Arrive at that point where you embrace uncertainty</p> <p>Faith- structure much looser now</p>
<p>Family and replenishment, maintaining spiritual integrity</p>	<p>A: Yes, I've got one or two friends who... through very different life stories have come to similar sorts of conclusions. And so, you know, I've got a handful of friends who I could talk about that with. And <i>I mean I talk to my wife</i>, you know, although I think she's more certain in her beliefs than I am.</p> <p>Q: Has she had a similar journey to them?</p> <p>A: I mean she's a nurse but</p>	<p>Handful of friends I can talk about that (<u>faith</u>) with</p> <p>Talk to my wife she's more certain in her beliefs than I am</p>

<p>Family and replenishment, maintaining spiritual integrity</p>	<p>she's worked much more in diabetes so she's not had to deal so much with some of the things I've had to deal with in my sort of work. But I mean <i>she's very understanding so I can talk to her about anything, anything goes</i>, you know. So I find that useful. But yes I think you do have to find people who you can actually talk to and connect with about those things.</p> <p>Q: Things I've got here are peer support and personal reflection and, as you've said, those who you can talk things through - questions of faith. Are there any other ways that you find helpful.... that help to strengthen your personal resources in dealing with some of the challenges that you find and given you are still here in palliative care and have a long history in palliative care, somehow it seems you've got through that...?</p> <p>A: Yes, I'm quite an introverted person in the sense that I need space to myself and so every ... I don't like to leave it too long but around about every couple of months <i>I'll go away for a weekend in retreat</i>, and just find time to completely... I'm doing that this weekend actually. <i>Where I'm just on my own and I just find the space to be by myself and not to have to think about anything particularly but just to go for long walks or to just be in my own company and I might sit in silence, look at the view, just try and reconnect with myself, get in touch with myself again a little bit. Because quite</i></p>	<p>You do have to find people who you can actually talk to and connect with about those things</p> <p><u>Personal reflection</u></p>
<p>Family and replenishment, maintaining spiritual integrity</p>	<p><i>Where I'm just on my own and I just find the space to be by myself and not to have to think about anything particularly but just to go for long walks or to just be in my own company and I might sit in silence, look at the view, just try and reconnect with myself, get in touch with myself again a little bit. Because quite</i></p>	<p>Introverted person – Need space to myself –</p> <p>Go away for weekend retreats</p> <p>On my own find space to be myself</p> <p>Reconnect with myself</p>

<p>Family and replenishment, maintaining spiritual integrity</p>	<p><i>often when you're just dealing with people, tasks and things, you feel as if you're part of a process, you aren't actually really feeling in touch with yourself, not feeling grounded in yourself. And I find that those times I can bring myself back into myself</i> and I can feel myself growing back into my own skin. If that makes any sense? And it's at that time that a lot of the issues that I might have been facing just get processed, even without me consciously thinking about them they get processed because I'm having that quietness and silence and, yeah... I think that's quite important to me. <i>But I think one thing that's massively important, and I think that loads of people would tell you this in palliative care, is to have a sense of humour</i> as well. <i>If you haven't got a sense of humour you're doomed!</i></p> <p>Q: I think nurses are noted for black humour, aren't they, but I think it comes into its own in palliative care doesn't it.</p> <p>A: So a sense of humour is vitally important and, you know, <i>I try and watch the comedies as much as I can and have a really good laugh because I think that just releases so many good chemicals and they're so good for you. And to be with friends who you can just be completely yourself with, be the biggest fool, and just have a really good laugh, a real belly laugh.</i> When I was in Ecuador part of my work was setting up support groups for people with HIV in</p>	<p>Quite often when dealing with people, tasks, things you feel as if you are part of a process</p> <p>I can find myself growing back into my own skin</p> <p>A lot of the issues I have been facing get processed without me consciously thinking about them</p> <p>A sense of humour-massively important Without <i>Humour</i> 'doomed'</p> <p>Comedies Good laugh releases So many good chemicals</p> <p>To be with friends who you can be completely yourself with</p>
<p>Family and replenishment, maintaining spiritual integrity</p>	<p><i>releases so many good chemicals and they're so good for you. And to be with friends who you can just be completely yourself with, be the biggest fool, and just have a really good laugh, a real belly laugh.</i> When I was in Ecuador part of my work was setting up support groups for people with HIV in</p>	<p>To be with friends who you can be completely yourself with</p>

	<p>the community and HIV was very stigmatised in Ecuador so quite often people wouldn't even tell their family members that they were HIV positive, it was that secret. And part of our work was to try and connect with these people who were hidden away, were HIV positive, but didn't know where to go for support help and so we did a lot of marketing to try and make sure people joined these support groups but in a very secret way – that they felt safe. And I remember one particular group who... they were a very diverse group... and you can imagine what they were like when they first meet someone else with HIV and they can be open about it, and suddenly you know they can be themselves, and this particular group there must have been about ten of them. After about 6 months of meeting up together and talking and really opening up and really getting to know each other and they were like new families to each other, and I remember we went away for a weekend with this group, just up into the mountains, and I have never laughed so much in my whole life, literally just crawling on the floor laughing, we just had such fun. And you could see the laughter was actually doing people so much good – we also cried during that weekend, you know we had moments of real tears – but the laughter was the thing that we will never forget from that weekend, and I keep in contact with some of that group and we still talk about that weekend. And the thing that stands out was all the laughter, the</p>	
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	<p>humour and the crazy jokes we played on each other, it was great. So I think those things... I think laughter actually brings connections with people as well. And without it this world would be pretty gloomy place really.</p> <p>Q: We can end on a humorous note. Thank you very much.</p>	<p>Laughter actually brings connections with people</p>
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APPENDIX 4

Biographical Information to be collected at interview

Code number:

Age:

20-30

30-40

40-50

50-60

> 60

Gender:

M

F

Professional Qualifications:

Title	Institution/Awarding Body	Date

Posts held since qualification as RGN:

Post	Institution	Type of experience	Start Date	End Date

Post registration training/education in:

	Institution	Content	Date
Spirituality/ spiritual care			
Loss			
Psychosocial care			
Palliative care			
Other			

APPENDIX 5

PARTICIPANT INFORMATION SHEET

Study title

Understanding psychosocial and spiritual issues in relation to coping in situations of chronic and terminal illness.

I would like to invite you to take part in the above research study. Before you decide to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please do not hesitate to ask me if there is anything that is not clear or if you would like further information to help you make your decision. You can contact me either by telephone on 01227 782627 or by e-mail: wendy.greenstreet@canterbury.ac.uk. I am a member of staff at Canterbury Christ Church University, employed as a Principal Lecturer in the Department of Nursing and Applied Clinical Studies, Faculty of Health and Social Care. This research constitutes a part time MPhil/PhD study that is to be completed by 2012 and is sponsored by the University. It is a qualitative study that uses interviews to explore how nurses use spirituality in their day-to-day clinical practice. The research has been reviewed and approved by **** **** Research Ethics Committee.

The Purpose of the Study

The Department of Health Working Paper concerning End of Life Strategy (September 2006) acknowledges that many patients have unmet spiritual and psychological needs. In exploring the significance of spirituality to nurses providing end of life care, this study may give rise to new knowledge about what and how nurses believe they contribute to these aspects of care in both institutional and community settings. The aim of the study, is therefore focused on gaining a better understanding of nurse's perceptions of spirituality, the extent to which they are able to facilitate spirituality as a source of coping in those facing loss(es) associated with chronic and terminal conditions and how nurses use their personal resources in the delivery of care.

Implications of Participating

Participants will be drawn from community, care home and hospice settings. These sites have been chosen as the most likely practice environments involved in the situations relevant to this research, where nurses care for those adjusting to various forms of loss associated with chronic and terminal illness. Specifically, nurses with at least three years experience and currently involved with end of life care in either the Heart of Kent Hospice, or West Kent Primary Care Trust Rapid Response out of hours team or Gavin Astor House Nursing Home who are willing to contribute are invited to participate.

If you decide to participate you will be asked to take part in an individual interview lasting about an hour. Participants can chose to withdraw from interview at anytime. Topics that will be addressed at interview are

spirituality, loss and personal resources. The interview will be recorded on audio tape for later transcription. I have negotiated with your managers involved in the study that these interviews can take place at your place of work in an area that allows privacy. You will also be asked to complete a brief questionnaire to provide information regarding age, gender, professional qualifications, posts held since qualification as a registered nurse and any relevant post registration training or education that you have undergone.

If you agree to take part in this study all information which is collected about you will be kept strictly confidential. Any information relating to you will have all personal details (name, etc.) removed so that you cannot be identified from it. On completion of the research the interview tapes will be destroyed. A summary of findings from data analysis will be presented at staff meetings at participating institutions, in this way participants will be aware of the outcome of this research as it unfolds. It is also anticipated that the study results will be published in professional journals. All direct quotes used in publication will be anonymised.

Thank you for taking the time to read this information. Participation in this study is voluntary. If you wish to take part you will need to sign the attached consent form. You will still be free to withdraw at any time and without giving a reason.

Version 2
2-2-09

APPENDIX 6

Participant Identification Number for this study:

CONSENT FORM

Title of Project:

Name of Researcher:

Please

initial box

I confirm that I have read and understand the information sheet dated (version) for the above study and have had the opportunity to ask questions.

☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. ☐

3. I understand that any data I have provided for this study will be published only in an anonymised form and that I will not be identified within it.

☐

4. I agree to take part in the above study.

☐

Name of Participant

Date

Signature

Researcher

Date

Signature

APPENDIX 7a

Descriptive Exploratory Comment

Emergent Themes	Transcript 1	Exploratory comments
	<p>anything, I suppose, metaphysical? To do with...</p> <p>Q: Tell me then what do you understand by metaphysical?</p> <p>A: Right... it's perhaps not easy to define. You could say like, as people we do have our... anything that is non physical, but.... emotions, beliefs, values, I am aware that it's possibly difficult to sort of define it.</p> <p>Q: Yes, I think it is difficult. You mentioned previously your strict religious upbringing, can you give a bit more detail about that?</p> <p>A: I can. So I grew up in Holland and was brought up in a strict Calvinist protestant environment. Which, when I was a child, I thought of very positively, so...</p> <p>Q: Tell me a little bit about that.</p> <p>A: So, what shall I...? Right. Probably sort of quite fundamentalist Christian, you know, the Bible was... everything in the Bible was... that was exactly the Word of God, and everything in there was absolutely right. And apart from that we used to read the Bible every day and pray every day, pray for every meal, go to church twice every Sunday, go to Sunday school when I was from a certain age, I think it must have been about 5 or 6. And when I was a teenager you had sort of groups for teenagers in the church. And I suppose that's about it. And I suppose I didn't really question too many things until I was I don't know, 18 or 19.</p>	<p>Not easy to explain</p> <p>Non physical aspect- emotions values belief</p> <p>Holland -Calvinist protestant-positive</p> <p>Quite fundamentalist Christian- Bible Exact word of God read every day-pray every day, every meal, church x 2 on Sunday</p> <p>Didn't question until 18or 19</p>

APPENDIX 7b

Descriptive and Linguistic Exploratory Comment

Emergent Themes	Transcript 1	Exploratory comments
	<p>anything, I suppose, metaphysical? To do with...</p> <p>Q: Tell me then what do you understand by metaphysical?</p> <p>A: Right... it's perhaps not easy to define. You could say like, as people we do have our... anything that is non physical, but.... emotions, beliefs, values, I am aware that it's possibly difficult to sort of define it.</p> <p>Q: Yes, I think it is difficult. You mentioned previously your strict religious upbringing, can you give a bit more detail about that?</p> <p>A: I can. So I grew up in Holland and was brought up in a strict Calvinist protestant environment. Which, when I was a child, I thought of very positively, so...</p> <p>Q: Tell me a little bit about that.</p> <p>A: So, what shall I...? Right. Probably sort of quite fundamentalist Christian, you know, the Bible was... everything in the Bible was... that was exactly the Word of God, and everything in there was absolutely right. And apart from that we used to read the Bible every day and pray every day, pray for every meal, go to church twice every Sunday, go to Sunday school when I was from a certain age, I think it must have been about 5 or 6. And when I was a teenager you had sort of groups for teenagers in the church. And I suppose that's about it. And I suppose I didn't really question too many things until I was I don't know, 18 or 19.</p>	<p><i>Pause</i></p> <p>Not easy to explain <i>Reflected in thoughtful and hesitant</i> Non physical aspect- emotions values - belief</p> <p>Holland -Calvinist protestant-positive</p> <p><i>Pause</i></p> <p><i>Hesitant</i> Quite fundamentalist Christian- Bible Exact word of God read every day-pray every day, every meal, churchx2 on Sunday</p> <p><i>Laugh</i> didn't question until 18or 19</p>

APPENDIX 7c

Descriptive, Linguistic and Conceptual Exploratory Comment

Emergent Themes	Transcript 1	Exploratory comments
	<p>anything, I suppose, metaphysical? To do with...</p> <p>Q: Tell me then what do you understand by metaphysical?</p> <p>A: Right... it's perhaps not easy to define. You could say like, as people we do have our... anything that is non physical, but.... emotions, beliefs, values, I am aware that it's possibly difficult to sort of define it.</p> <p>Q: Yes, I think it is difficult. You mentioned previously your strict religious upbringing, can you give a bit more detail about that?</p> <p>A: I can. So I grew up in Holland and was brought up in a strict Calvinist protestant environment. Which, when I was a child, I thought of very positively, so...</p> <p>Q: Tell me a little bit about that.</p> <p>A: So, what shall I...? Right. Probably sort of quite fundamentalist Christian, you know, the Bible was... everything in the Bible was... that was exactly the Word of God, and everything in there was absolutely right. And apart from that we used to read the Bible every day and pray every day, pray for every meal, go to church twice every Sunday, go to Sunday school when I was from a certain age, I think it must have been about 5 or 6. And when I was a teenager you had sort of groups for teenagers in the church. And I suppose that's about it. And I suppose I didn't really question too many things until I was I don't know, 18 or 19.</p>	<p><i>Pause</i></p> <p>Not easy to explain <i>Reflected in thoughtful and hesitant</i> Non physical aspect- emotions values belief So- <u>this is spirituality?</u></p> <p>Holland -Calvinist protestant-positive</p> <p><u>Used to be positive?</u> <i>Pause</i></p> <p><i>Hesitant</i> Quite fundamentalist Christian- Bible Exact word of God read every day-pray every day, every meal, churchx2 on Sunday <u>Intense religious upbringing</u></p> <p><i>Laugh</i> didn't question until 18or 19 <u>Rejection late adolescence – laughter suggest surprised it took her so long to question?</u></p>

APPENDIX 7d

Emergent Themes

Emergent Themes	Transcript 1	Exploratory comments
Non religious spirituality	<p>anything, I suppose, metaphysical? To do with...</p> <p>Q: Tell me then what do you understand by metaphysical?</p> <p>A: Right... it's perhaps not easy to define. You could say like, as people we do have our... anything that is non physical, but.... emotions, beliefs, values, I am aware that it's possibly difficult to sort of define it.</p>	<p><i>Pause</i></p> <p>Not easy to explain <i>Reflected in thoughtful and hesitant</i> Non physical aspect- emotions values belief So- <u>this is spirituality?</u></p>
Religious	<p>Q: Yes, I think it is difficult. You mentioned previously your strict religious upbringing, can you give a bit more detail about that?</p> <p>A: I can. So I grew up in Holland and was brought up in a strict Calvinist protestant environment. Which, when I was a child, I thought of very positively, so...</p>	<p>Holland -Calvinist protestant-positive</p> <p><u>Used to be positive?</u> <i>Pause</i></p>
Religion challenged	<p>Q: Tell me a little bit about that.</p> <p>A: So, what shall I...? Right. Probably sort of quite fundamentalist Christian, you know, the Bible was... everything in the Bible was... that was exactly the Word of God, and everything in there was absolutely right. And apart from that we used to read the Bible every day and pray every day, pray for every meal, go to church twice every Sunday, go to Sunday school when I was from a certain age, I think it must have been about 5 or 6. And when I was a teenager you had sort of groups for teenagers in the church. And I suppose that's about it. And I suppose I didn't really question too many things until I was I don't know, 18 or 19.</p>	<p><i>Hesitant</i> Quite fundamentalist Christian- Bible Exact word of God read every day-pray every day, every meal, churchx2 on Sunday <u>Intense religious upbringing</u></p> <p><i>Laugh</i> didn't question until 18or 19 <u>Rejection late adolescence – laughter suggest surprised it took her so long to question</u></p>

APPENDIX 7e

Colour Coding of Illustrative Excerpts of Super-ordinate Theme

Emergent Themes	Transcript 1	Exploratory comments
Non religious spirituality	anything, I suppose, metaphysical? To do with...	<i>Pause</i>
	Q: Tell me then what do you understand by metaphysical? A: Right... it's perhaps not easy to define. You could say like, as people we do have our... anything that is non physical, but.... emotions, beliefs, values, I am aware that it's possibly difficult to sort of define it.	Not easy to explain <i>Reflected in thoughtful and hesitant</i> Non physical aspect-emotions values belief So- <u>this is spirituality?</u>
Religious	Q: Yes, I think it is difficult. You mentioned previously your strict religious upbringing, can you give a bit more detail about that? A: I can. So <i>I grew up in Holland and was brought up in a strict Calvinist protestant environment. Which, when I was a child, I thought of very positively, so...</i>	Holland -Calvinist protestant-positive <u>Used to be positive?</u> <i>Pause</i>
	Q: Tell me a little bit about that. A: So, what shall I...? Right. Probably sort of quite fundamentalist Christian, you know, the Bible was... everything in the Bible was... that was exactly the Word of God, and everything in there was absolutely right. And apart from that we used to read the Bible every day and pray every day, pray for every meal, go to church twice every Sunday, go to Sunday school when I was from a certain age, I think it must have been about 5 or 6. And when I was a teenager you had sort of groups for teenagers in the church. And I suppose that's about it. <i>And I suppose I didn't really question too many things until I was I don't know, 18 or 19</i>	<i>Hesitant</i> Quite fundamentalist Christian- Bible Exact word of God read every day-pray every day, every meal, churchx2 on Sunday <u>Intense religious upbringing</u> <i>Laugh</i> didn't question until 18or 19 <u>Rejection late adolescence – laughter suggest surprised it took her so long to question</u>
Religion challenged		

APPENDIX 8

Biographical Summary of Participants

	Age in Years	Years as RGN	Post	Current Role	Study Care of the Dying	Study of Loss	Study of Spiritua l Care
1	50-60	36	Hospice 6 yrs	Staff Nurse	x	x	
2	60+	43	Hospice 9 yrs	Staff Nurse	x	x	
3	30-40	7	Nursing Home 6 yrs	Ward Manager	x	x	x
4	60+	46	Nursing Home 12 yrs	Staff Nurse	x	x	
5	30-40	19	Nursing Home 10 yrs	Night Sister	x		x
6	40-50	22	Hospice 4 yrs	Manager	x	x	
7	40-50	19	Hospice 5 yrs	Ward Manager	x	x	x
8	40-50	20	Hospice 1 yr	Education Manager	x	x	x
9	50-60		District Nurse	Sister	x		
10	40-50	5	Community 5 yrs	Staff Nurse	x		
11	20-30	4	Community 1 yr	Staff Nurse			
12	20-30	5	Community 1 yr	Staff Nurse	x		